



Photo: www.garethbarton.com

A BETTER LIFE TOGETHER

Faith communities and people with disabilities

A resource for faith leaders, people with disabilities and community carers in refugee and internally displaced persons camps



Background to this resource

This resource has been developed by the Anglican Alliance in partnership with the Bethesda Project in Muyinga and Bujumbura Anglican Dioceses, Burundi and the Zambia Anglican Council, as part of a project funded by the Humanitarian Innovation Fund (more detail below). Over six months the partners carried out participatory research with faith leaders, community carers and people with disabilities in refugee and Internally Displaced Persons' (IDP) camps in Burundi and Zambia. Through workshops and community work, they learnt about the situation of people with disabilities in these settings. In this way the resource was developed and tested in different contexts in each country. As the resource progressed it was shared and revised by specialists in refugees and protection, disabilities and development and faith and empowerment. We are grateful for the engagement of all these people, for their support, contribution, critical review and encouragement.

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The Humanitarian Innovation Fund (HIF) is a unique non-profit grant making facility supporting organisations and individuals to identify, nurture and share innovative and scalable solutions to the challenges facing effective humanitarian assistance. Visit www.humanitarianinnovation.org for more information.

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Foreward by Archbishop Albert Chama, Chair of the Anglican Alliance

We are all made in the image and likeness of God (Genesis 1: 26 a), who does not look on our outward appearance, but who looks upon the heart, on what is inside us. We believe that each of us is utterly precious and unrepeatable. There is no one else in the world like you, or like me and it is individuals whom God loves and longs to save. This is no less true of people who live with a disability.

This very practical resource pack has been designed to help you, as religious and community leaders, to understand people who live with disability and to help you improve their lives.

In this resource pack, you will find some very helpful background information on the various disabilities you will come across and how those disabilities affect people's lives. But the pack goes much further and offers many useful tools to

- help you gather information about disability,
- to teach what we believe about human nature
- to communicate that message to your community
- and to help you find practical ways to make a difference.

The resource pack has taken a long time for us to get right and I am very grateful to the Anglican Alliance and the Dioceses of Zambia and Burundi, various refugee agencies and the many people we met, who have a disability, but who taught us so much.

I commend this resource to you, warmly with prayer and in faith, trusting that it will help you affirm God's image in everyone and do much to build the Kingdom where you are.

May God bless you in all you do, to His glory.

THE MOST REVD ALBERT CHAMA,
ARCHBISHOP AND PRIMATE OF CENTRAL AFRICA,
CHAIRPERSON OF THE GLOBAL BOARD OF THE ANGLICAN ALLIANCE.

Anita, from DRC, is active in her church community, despite her mobility problems due to polio. She is encouraged by visits from her church community, including the children.

She would love to continue her education, if only she could get to the school. The school is too far away in this camp, so she has not been since she moved here three years ago.

Photo: Anglican Alliance



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Introduction

This resource has been developed to enable faith communities to engage better with and support people with disabilities, particularly in the context of refugee camps and internally displaced persons (IDP) camps in Africa. The resource can be used by individuals to reflect on the issues of disability and how faith groups can act to engage better with and support people with disabilities. The resource explains the challenges that people with disabilities face but also highlights their capacities and contributions they can make to enrich your community.



Drawing: Petra Röhr-Rouendaal

Our hope is that you will be inspired to get a group from local faith communities together with people with disabilities to work through the resource and start to engage more with the people with disabilities in your local community. Together you can start a process that will raise awareness of disabilities, improve the quality of life for people with disabilities and their families, and drive a process of inclusion and equal opportunities for the benefit of the entire community, people with disabilities and people without disabilities. Together you will be able to advocate with and for people with disabilities on the issues that are a priority for them in your setting. You will be able to plan together how best to protect people with disabilities who are vulnerable, to enable them to live life without fear of abuse or violation.

At the end of the resource are a series of Annexes with examples, exercises and tools to help you engage more fully with people with disabilities in your community, to allow you all to have **“a better life together”**.

Disabilities

What are disabilities?

“Disabilities” is a broad term that covers impairments, activity limitations, and participation restrictions.

1. An impairment is a problem in body function or structure, for example a cataract that stops light going into the eye so it cannot see shape and detail normally
2. An activity limitation is a difficulty a person has to do a task or action, such as is not able to read or move around
3. A participation restriction is a problem experienced by an individual in involvement in life situations, for example exclusion from school

This definition focuses on measuring difficulties and barriers (b and c) to participation caused by the impairment (a), rather than focussing on the medical impairment itself. It is based on the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organisation (WHO, 2001).

This classification system records higher levels of disability than a medical model. This difference was noticed during community work in Zambia, where national statistics report 2% disability, against worldwide average reports of 15%. More information about this can be found in Annex 1.

As we want to see everyone disabled and non-disabled living life to the full, so the tools in this resource use the ICF classification of disabilities to identify all people with disabilities that limit their daily activities and restrict their participation in community life.



Drawing: World Health Organisation



Drawing: Petra Röhr-Rouendaal

With good health care, a well planned environment and a supportive community, disabilities may not limit and restrict daily life. These people with disabilities can enjoy life to the full. However, this is not always the case.

Jesus says: I have come that they may have life, and have it to the full.

Christian text: John 10:10

Some people have one or more impairments that together with community attitudes, a poor environment and inadequate healthcare mean that their daily life is severely restricted. The tools and care profile in this resource try and capture this variation in severity of impairment, limitation and restriction.

During field visits in Burundi and Zambia, it was clear that recorded disability levels were very low compared to those expected. This is because only the most severe and limiting disabilities are recorded by the authorities. The overwhelming response to profiling in Kinama refugee camp, Burundi, suggests that even severe and limiting disabilities are not all recorded. There was clearly felt to be unrecorded disabilities and a keen desire for increased support for people with disabilities and their carers.

This highlighted the need for community work to identify people with disabilities, who may be hidden at home and marginalised, not able to access support, even if severely disabled. Here drama was a good medium to raise awareness and change attitudes so that every person is valued and respected. A drama about a disabled boy hidden at home is given in the Annex ca, together with notes on preparing dramas in Annex 7c.

Prominent religious leaders, including the much respected late Grand Sheik Sayyed Mohammed Tantawi, of Cairo's Al-Azhar Mosque and the Coptic Pope Shenouda III, declared publicly that harmful traditional practices have "no foundation in religious texts" of either Islam or Christianity.

Sheikh Tantawi stated: "Parental care is the main foundation for protecting children and enabling them to enjoy the rights guaranteed by Islam. But society and state institutions also have a key role in this regard. For all children to acquire such rights without discrimination, lawmakers must also ensure children are protected from physical or moral humiliation."

Language:

There is immense power in language to convey attitude, belief systems and the messages we want to send out to others. Therefore we need to be aware of the words or phrases we choose so as not to hurt or insult other people or mark them out as separate from everyone else.

Language is ever changing and what may have been acceptable yesterday may be unacceptable today. Words like "cripple", "retard", "deaf and dumb" are hurtful and inappropriate. Even between countries, different terms are acceptable or felt to be stigmatising. Thus in the United States, people prefer "people with disabilities" over "disabled person", while in the United Kingdom, people prefer "disabled person" as it reflects the fact that they are disabled by society and their environment not just their disability. In Burundi, people preferred "people living with disabilities", "personne vivant avec handicaps" over "personne handicapée"

Local languages may have their own terms that may be common use but still lack respect and reflect the prejudice against people with disabilities. It is important to challenge such expressions that support prejudice and misconceptions and instead encourage a language that is inclusive and as respectful as any men, women and children deserve.

People with disabilities face many barriers - physical, social, psychological and environmental - that make it very difficult for them to participate fully in daily life. People with disabilities often have limited or no access to education, health care, and employment and are often socially excluded or even mistreated. These barriers put people with disabilities at a particular risk of increased poverty. However, this should not happen, as people with disabilities have rights.

Rights of people with disabilities

The UN convention (agreement) on the rights of persons with disabilities sets out what countries have to do to make sure that disabled people have the same rights as everybody else.

The basic ideas are:

- People are free to make their own choices
- No one will be discriminated against
- Disabled people have the same rights to be included in society as anybody else
- Disabled people are to be respected for who they are
- Everyone should have equal opportunities
- Everyone should have equal access
- Men and women should have equal opportunities
- Disabled children should be respected for who they are as they grow up

This is taken from the EasyRead guide to the United Nations Convention on the Rights of Persons with Disabilities, which can be found here: http://www.fedvol.ie/_fileupload/Next%20Steps/EasyReadUNConvention.pdf

A full list of the different articles of the convention are given in the Annex 2 and the full agreement, the United Nations Convention on the Rights of Persons with Disabilities, is on the UN website at: www.un.org/disabilities

Hadith Qudsi 17 states ‘O My servants, I have forbidden oppression for Myself and have made it forbidden amongst you, so do not oppress one another.’

Muslim text: Hadith Qudsi related by Muslim, Rimidhi and Ibn Majah

The stranger who resides with you shall be to you as one of your citizens; you shall love him as yourself, for you were strangers in the land of Egypt.

Jewish and Christian text: Leviticus 19:33-34

In everything, do to others what you would have them do to you.

Christian text: John 10:10

Ye have been forbidden in the Book of God to engage in contention and conflict, to strike one another, or to commit similar acts whereby hearts and souls may be saddened.

Bahá’í text: The Kitab-i-Aqdas, 72-7398

Some facts about disabilities



15% of the population worldwide live with a disability, that is 1 person in every 6, but this increases to 18% in low income countries, about 1 in every 5 people.

80% of people with disabilities live in developing countries, that means that here in a refugee/IDP camp, the rate is likely to be higher still, as disasters create new disabilities, as well as increase the vulnerability of disabled people.

Image: Light for the World

Rates of disability are increasing as people are living longer and there is an increase in chronic health conditions worldwide. War is also a major cause of disability. For every child killed in warfare, three are injured and permanently disabled.

Disabled people often do not receive needed health care: People with disabilities are four times more likely to report that they are treated badly and nearly three times more likely to be denied health care. So disability can cause severe health problems. And because poor people often cannot access or afford health care health problems can cause disability.

Children with disabilities are less likely to attend school: More than 90% of disabled children in developing countries do not attend school. Only 1% of disabled women are literate. This illiteracy in turn increases reliance on others and vulnerability of disabled people.

Disabled women and children are often victims of violence - 50% of disabled women worldwide experience abuse; disabled women are between 1.5 - 10 times as likely to be physically or sexually abused as a non-disabled woman; disabled children are 4-5 times more likely to experience violence and sexual abuse than non-disabled children.

People with disabilities comprise 20% of the poorest of the poor. Generally you are much more likely to have a disability if you are:

Poor • Female • Older



Drawing: Petra Röhr-Rouendaal

So you can see that disability and poverty are part of a cycle:

Disability increases the risk of poverty



Poverty increases the risk of disability

Image: Light for the World

Effects on the family

Many disabled people rely heavily on carers, particularly the very young or very old (which many disabled people are). They may not be able to feed themselves or to use sanitation facilities without help. The constant caring over many years can cause burn-out (severe exhaustion) in the carers. It can also put a lot of stress on the family, which can lead to family break up.

Families as well as people with disabilities may be marginalised and discriminated against. This leads to isolation and increased pressure on the family. People with disabilities may be neglected or abused, even within the family. The most vulnerable often suffer the most, may not get food when there is not much to go round, may not be cared for sufficiently and may be victims of abuse both physical and sexual.

Lack of acceptance and support from the community increases these risks. Faith communities have an important role to play to change attitudes and support people with disabilities and their families.

Types of disability

There are many different types of disabilities and not all of them are immediately visible. Here are some examples of impairments that people may have and that affect their daily lives:

- Difficulty seeing
- Difficulty hearing
- Difficulty speaking, being understood
- Difficulty understanding, remembering, concentrating, learning
- Difficulty moving and reaching/using objects
- Difficulty coping with one's environment

These impairments can affect people differently. The tools in this resource aim to identify all people with disabilities, so the degree of the impairments and activity limitation are recorded to indicate the severity of the disabilities (none, a little (mild), a lot (severe)). Two or more severe impairments or limitations would be considered a severe disability, while one severe impairments or limitations would be a moderate disability. These are the two categories that would be recorded by the agencies.

These impairments can be the result of:

- Injury/trauma (like loss of limb)
- Mental trauma (like violence and rape)
- Poverty (lack of nutrition, lack of access to medical care)
- Ignorance (lack of awareness of nutrition, hygiene, antenatal care)
- Difficulties during pregnancy or birth
- Disease (like polio, river blindness)
- Chronic (long term) disease (like HIV-AIDS, diabetes, epilepsy)
- Old age (like painful joints or stiffness)
- Domestic violence (mental as well as physical)
- Traditional or wrongfully applied medicine

A man should not project excessive fear in his household.

Jewish text: Talmud Bavli, edited 8th century C.E Gitten 6b

Some examples of the effects of different severities of disabilities are shown here:

- Sarah has very painful joints in her left hand and cannot use it to hold things, but this does not affect her daily life very much because she is very clever and compensates well
- John became deaf as a child due to being given the wrong dose of malaria treatment. He is very good and can read people's lips and his family and friends have learned to use some form of sign language. However, he has great difficulty with lessons at school when the teacher does not face him. He relies on people being considerate of his specific communication needs – but people often forget
- Samuel has very stiff and tense muscles, and his arms and legs just don't work well. He cannot move much on his own and even speak. To eat, drink and do self-care is extremely difficult for him. He needs help with everything.
- Fidele has albinism and no one even thinks he has a disability. But people with albinism often have poor eye sight and their skin gives no protection against the sun. He has sores on his face and arms and he knows he can get skin cancer. What's worse, people make fun of him, often call him a pig and people say terrible lies that body parts of an albino can make you rich – so Fidele and his family are very afraid.

So you see the range of limitations that Sarah, John, Samuel and Fidele's disabilities have on how they can participate in daily life, especially if other people cannot or do not want to help or make adjustments that would better include people with disabilities.

Some people have more than one problem and this usually makes things more difficult. Like Mary, now she is older she finds it difficult to walk far, she does not see very well, but also she gets confused easily and forgets things, so she needs help with many things.

Here are some examples of different disabilities:



Seeing



Hearing & Speaking



Moving



Photos: Anglican Alliance & Bridget Hathaway

However, there are some disabilities that are not so obvious. Some people have learning disabilities. People often think people with intellectual disabilities cannot learn at all and are stupid and useless but this is not true. They just need more guidance and patience.

Other people may have mental health problems which are very different from learning disabilities. People with mental health problems may have difficulty that relate to other people; they may feel overwhelmed by daily challenges and appear aggressive or withdrawn or confused.

Causes of disability

Some disabilities start at birth, but most come later from disease, injury or old age. With good health care many disabilities can be prevented or their impact can be mitigated. A full table with causes of disabilities, possible prevention and mitigating impact can be found in Annex 3.

There are 39 million people around the world who are blind, it is a shocking that 80% of these can be cured or could have been prevented.

Mostly people know how and when they got their disability, but they may not understand the cause, particularly if they have not had access to medical care before. Some disabilities, for example mental health problems, are often caused by traumas of conflict, violence and displacement.

Impact of disabilities

Being able to participate in daily life is often not limited by the type and severity of the disability. Very often, the difficulties people with disabilities face are caused by prejudice, lack of knowledge and understanding.

The limitation is often other people's attitudes. It can also be due to lack of simple adaptations that would allow participation. But the result is the same, people with disabilities are often excluded.

It should not be so, and you and your faith communities can help change things.

*Mother using Personal Energy Transportation (PET) to move around with her child,
Photo: PET Zambia*



SCENARIO ONE: “Emmanuel, are you coming to school?” shouted Reverian “Today we will learn about things in science!” Emmanuel looked angry. Why did Reverian bother to ask? Of course he wasn't going to school; he never had gone to school, and as far as he could think he never would go to school. When he was 3 years old he had been very ill with meningitis, and although he recovered well he was left without his sight. Here at the camp no-one had asked his parents about him, no-one in authority had mentioned him. He began to wonder, had his parents even registered him? If he wasn't registered at the camp then he didn't exist, did he? He was only a child, how could he ask his parents such a question? These thoughts went round and round his head.

And his disciples asked him, “Rabbi, who sinned, this man or his parents, that he was born blind?” Jesus answered, “It was not that this man sinned, or his parents, but that the works of God might be displayed in him.”

Christian text: John 9:2-3

Social and physical barriers

Social barriers and prejudice can affect disabled people every day. Non-disabled people's attitudes marginalise them. This is seen in how they are treated by their families, communities and the agencies that provide support and services to the camp.

- Are they respected?
- Can they participate in family activities and decisions?
- Can they participate in community activities?
- Are they treated as any other family or community member?
- Are children with disabilities able to go to school?
- Can they play with other children?

As well as social barriers there are often physical/practical barriers to participating fully in daily life. Here are some examples of situations that lead to people with disabilities not being able to participate:



Drawing: Petra Röh Rouendaal

Problem	Impact
Camp offices are a long way from their house	Someone with difficulty moving won't be able to get there easily
Information about food or NFI distributions and other activities are not accessible	Blind people cannot read/see announcements and information on posters or leaflets; deaf people cannot hear announcements over radio or loudspeakers
Camp offices are always busy and noisy	Someone with difficulty communicating won't get any attention, if they are deaf or blind for example. Similarly someone who is confused or does not like being in crowded places will find it very difficult to cope
Distribution of food and NFI take a long time	Someone who is elderly or someone weak from AIDS cannot manage to wait in the sun for hours
The clinic has steps to get in	Someone with difficulty walking finds it hard to get into the clinic
Health care/camp staff are too busy or do not know how to communicate with disabled people	Deaf people or people with communication problems find it difficult to express their needs and to find staff who take the time to try alternative communication methods
Safety measures are often not in place to protect, in particular, disabled women and girls from sexual violence	While this is risk for all women and girls, disabled women and girls are more at risk because they cannot see or hear an attacker, can't run away or defend themselves or don't understand the risk (as an intellectually disabled woman or girl). The attackers feel safe to attack disabled women and girls because their disability makes them poor witnesses (can't describe assailant because of blindness or are not believed when they have learning disabilities) or because it is they expect no one will care anyway
People do not think someone with disabilities has the same needs and abilities as everyone else	A child who is deaf or blind may not have the opportunity to go to school.
A person with disabilities may not be invited to join the choir or be a camp leader	A child with disabilities may not be given as much food as others when there is little food

SCENARIO TWO: Water! No-one can live without water can they? Mama Flora looked at the empty water carriers and pot and went in search of her firstborn, Flora. Flora had wandered off again just when she needed her. She loved Flora despite her slow mind and strange ways. Since birth she had never been like other children, and now at 18 years old she was beautiful but with the mind of a young child. Mama Flora relied on her daughter to help her collect water, especially as the water point was far from their house. She would be able to send Flora on her own to collect water if it had been nearby but it was dangerous to send her far away. Oh she had seen the look in the eyes of some of the men when Flora walked past them, a look that put fear into Mama Flora's heart. No! She would always have to accompany her daughter to collect water.

Disasters and emergencies

People with disabilities are particularly at risk during emergencies, such as natural disasters and conflict

- They may not receive information about the disaster and evacuations
- They may not be able to get to safety as easily as others
- They may lose contact with close family and care givers

People can also become disabled during and after an emergency. There will be more injuries and lack of medical care can mean that even minor injuries may result in long-term disability.

Faith communities have a really important role to play at this time to ensure that people with disabilities get access to human rights such as:

Water – Food – Shelter – Latrines - Medical Service - Education – Non Food Items (NFI)

They may need help to ensure that they are registered to access these services, but also to ensure that they are safe. This was seen in reports after recent big emergencies:

- Great East Japan earthquake, 2011, the death rate amongst the total population of the coastal area of Miyagi prefecture was 0.8% while amongst registered disabled persons it was 3.5%
- Hurricane Katrina USA, 2004, 21.3-27.1% of the affected population had a disability
- Haiti earthquake, 2010, approximately 200,000 people are expected to live with long term disabilities as a result of their injuries
- Indian Ocean Tsunami, 2004, there was an estimated 20% increase in the number of persons with disabilities in affected areas

People with disabilities are often forgotten: People living with disabilities report that they are rarely consulted about their needs. Evacuation in the event of a sudden disaster is a prime example:

- 20% could evacuate immediately without difficulty
- 74% could evacuate with a considerable degree of difficulty
- 6% would not be able to evacuate at all

But if they are not considered, they are likely to be left behind. It is important to include people with disabilities in disaster preparedness planning. Here are some of the things that people with disabilities may not be able to access equally compared to other people in the refugee or IDP camp; things they may be excluded from, but that they have equal rights to:



water
supply



food



shelter



sanitation
& hygiene



medical
services

Children of God

Everyone is valued and loved

People with disabilities are like everyone else. Everyone has dreams, cares and needs. Neither disabled nor non-disabled people are all the same. We are all different.

We need to remember that each one of us, disabled or non-disabled, is special, valued and chosen by God. As people of faith we need to listen to God and learn from God. God sees us, not as disabled or useless but as precious and valued. We are all in the Image of God and can have a better life together.

Each person has a part to play in God's work here on earth. We are all parts of God's body with a job to do, whether disabled or non-disabled. We are all valued. In fact, those with disabilities can have special gifts which the community particularly value.

Service to others is important. Whether disabled or non-disabled we can serve others. We should all be willing to serve all people, whatever their situation and in order to do this we need to be united in purpose. We should be united by love, compassion and mercy.

Justice, mercy and compassion are important but love is key as from it flows respect and care.

Within the community, all have gifts to give and needs to be met.

Disabled people may have specific needs related to the type of impairment they have, but these needs can often easily be met if adjustments are made to services and we recognise disabled people as equal members of society. Disabled people must be included in daily life, not excluded. We are all God's children, made in the Image of God, and have the right to participate fully in daily life.

Verily, God does not look at your bodies or your appearance, but looks into your hearts.

Muslim text: Muslim, 2564

"Treat not others in ways that you yourself would find hurtful."

Buddhist text: The Buddha, Udāna-Varga 5:18

If one part of the body suffers, all the other parts suffer with it; if one part is praised, all the other parts share its happiness. All of you are Christ's body, and each one is a part of it.

Christian text: 1 Corinthians 12:26-27

The Compassionate One has mercy on those who are merciful. Show mercy to those on earth so that He Who is in the heavens (i.e. Allah) will bestow mercy on you.

Muslim text: Abu Dawud

Gifts and capacities

Like every member of the community, people with disabilities have capacities: gifts, skills, knowledge and experience. They might be using them now, but since many people with disabilities are overlooked, they may not have the opportunity to use them at the moment. Enabling disabled and non-disabled people to use their capacities to the full enriches and strengthens the community.

Here are some of the capacities that 15 people with disabilities shared during a community visit to Mahebe refugee settlement in Zambia in May 2014 (the larger the text, the more people reported this capacity):

singing
hair plaiting
listening
leading groups
teaching young people
evangelising
problem solving
sewing
fixing radios
church leader
praying
sharing history and culture
block leader counselling

It is hard for a person with disabilities and their family when they are not able to join in; when they are left out. As faith communities we are urged to care for one another and treat each other with respect, Mark 12:29-31. Doing this can transform the quality of life for a disabled person and their family. Just changing attitudes can have a huge impact.



Drawing: World Health Organisation

But each man has his own gift from God; one has this gift, another has that

Christian text: 1 Corinthians 7:7b

Aisha has always been busy, working on their small plot of land, milking the goat, caring for the family, but at 78 she is old and almost blind, she struggles to walk far. Escaping the rebels was hard, but she was lucky that the family helped her. Now in the camp, life is so different, she struggled, feeling isolated, till people got to know how good she was at listening and giving wise advice. Now she doesn't feel so isolated, people are always visiting to talk through their problems.

What can a faith community do?

As faith communities there is a lot that we can do. We can begin by seeing everyone as a Child of God (Galatians 3:26), by knowing our community, loving our people, showing love in both practical and spiritual ways and engaging with our disabled faith members to better understand how to include disabled people and their families in daily life.



Ali is not able to do anything for himself, having been very sick with malaria/meningitis when he was 3 years old. Zena, his mother, cares for him lovingly, but feels isolated.

Life could be very different for Zena, if she could meet with other parents caring for children with disabilities for support, or if her neighbours invited them for coffee, or if someone helped her during distributions, caring for Ali so she could collect her ration.

When you have a supper, ask poor people. Ask those who cannot walk and those who are blind.

Christian text: Luke 14:13

Since you are precious and honoured in my sight, and because I love you...

Jewish and Christian text: Isaiah 43:4a

The resource includes as annexes further resources to allow you to engage with your community:

- Examples of an agenda for a workshop using the resource and next steps to setting up a local committee and preparing an action plan (Annexes 4 and 10)
- Scenarios and dramas to introduce disability issues to the community (Annexes 6 and 7)
- Exercises to help you identify and prioritise the issues for people with disabilities and to plan what you can do together to change things, and to identify harmful behaviours and how to plan to protect people with disabilities from these (Annexes 8 and 9)
- Tools for identification and profiling people with disability to be able to prepare care profiles for them and learn about the key issues in your context (Annexes 12, 13 and 14)



Care profiles for people with disabilities (Annex 14)

What can a faith community do?

Welcome and care

- Seek out people with disabilities and their families, talk with them and learn about their situation
- Welcome people with disabilities and their families; they can feel isolated and excluded
- Offer pastoral support and encouragement
- Provide spiritual support and prayer
- Find out what their gifts are and use those gifts to build up our faith community

Learn about disabilities and consult disabled people

- Learn about disabilities, start by talking to people with disabilities and their carers
- Raise awareness about disabilities both in the community and those working in the camp

Concrete examples of awareness raising are:

- Put interest of people with disabilities on the agenda
- Use correct and appropriate language and discourage others from using derogatory terms
- Plan events with disabled people where they speak about their experience, both as disabled people and the barriers they encounter; and about their ways of dealing with every day challenges; but also about their skills and gifts
- Make sure that public information is reaching disabled people and demanding that information is made accessible, e.g. a number of different ways/media of disseminating; large print, bigger pictures; both print and auditory dissemination; buddy system to bring information to people who can't go to where information is being given
- Make sure to include disabled people in regular community events, as most people with disabilities have immense capacities if included in activities in church and community



Disabled people gather at the Anglican Church in Meheba refugee settlement, Zambia, photo: Anglican Alliance

What if you want to take this forward?

How you do this will depend on the local situation, including who is keen to be involved, local culture and the local setting (for example whether rural or town). The information here is a guide to get you thinking and planning. You can start in a small way and go out from your faith centre and then gradually cover more of the community. Others have chosen to try and cover the whole community rapidly, inviting people to come to a faith centre/building for profiling; they would then need to go house to house to identify any people with disabilities who are more housebound or hidden.

Invite people from the community, faith leaders, people with disabilities, community leaders, community carers, to a meeting. Introduce the idea and plan to hold a series of meetings/workshops to work through the resource together. An example of a workshop agenda is given in Annex 4. A good way to introduce disability issues is to use scenarios or dramas, some examples of scenarios and dramas are given in Annex 6 and 7 together with notes on how to prepare the dramas.

At the end you will be able to draw up an action plan for how you will take things forward, which might include setting up a committee and forming a local association to allow you to engage with regional or national disability organisations. An example of this is given in Annex 10.

Community engagement might look like this:

From the workshop participants get a team together and train them for working in the community to identify and profile people with disabilities and prepare care profiles. The identification tool is used to go from house to house, through gentle conversation to see if there is anyone in the household with disabilities, especially looking out for the hidden ones.

Once people with disabilities have been identified, arrange to go back and talk in more detail about the situation of the person or persons with disabilities in the household, using the profiling tool. The profiling will take longer and will be used to learn more about the situation of the person with disabilities to allow a care profile to be prepared, but will also inform the group about protection and advocacy needs locally. The identification tool, profiling tool, care profile and training notes can be found in the Annexes 11-14.

Before you go out into the community, meet with local authorities and the community and tell them about the activities. This will help build support for your activities and help people to welcome your visit. It is also important to discuss how the information you hear will be used, how and where it will be stored and who it will be shared with. People in the community need to have confidence that things they share will be kept confidential and that their personal story will not be shared without permission.



Profiling visit in Meheba refugee camp, Zambia

Before setting out, meet together for prayer, then in pairs, visit households locally. For the identification, you are wanting to visit every household. You may need to go back at different times to make sure it is a good time to speak with someone from each household. When you identify a household with someone with disabilities, arrange to come back and talk more with them. There are many questions and you need to fill one form for each person with disabilities, so this will be a longer visit. You will need to ensure at least one parent or carer is present when you talk with children.

From the completed profile form, you will be able to prepare a care profile (Annex 14) for each person with disabilities, a record for them of their impairment, history and treatment, the limitations and restrictions that they experience, but also of the capacity. This is to help them when they deal with the authorities and can include a photo and be laminated.

You will also begin to learn what the issues are that people with disabilities have locally, what they appreciate about what the faith groups are doing and what they feel faith groups could do more of or better. This will provide a good lead in to having a meeting or meetings with people with disabilities to prioritise the important issues that they would like the support of faith groups to change, their advocacy priorities. The advocacy exercise, in Annex 8, will help you identify what you can change and how, but also what you need to influence others to change, what would persuade them and who you might get to support you to influence them.

How you hold the meeting or meetings with people with disability will depend on your context. If you work in a small area, you could just have one meeting. If you have a lot of interest or your camp is spread over a large area, where it is hard for people with disabilities to get to a single point, it may be important to have several meetings. However, after holding one or several general meeting to learn about the situation and priorities of people with disabilities, it would be good to select a smaller group to take activities forward in more detail. In this case, twenty five to thirty people to represent a range of ages and disabilities and with a good gender balance would be good.

When planning activities, be aware of different disabilities and plan to include everyone, for example use pictures instead of words so people who are illiterate, speak different languages or have learning difficulties can fully participate. Think about how you include people who are blind or deaf or those with mental health difficulties.



Drawing: Petra Röh Rouendaal

Work with people with disabilities and their carers

Find out what barriers there are for disabled people in this camp that stop them from accessing services and participating fully.

Plan with disabled people what can be done to improve things

Providing support:

- Accompany disabled people to service provisions such as health clinics and school if they have mobility difficulties (including blindness), communication difficulties (including remembering things) or have routinely been ignored or mistreated;
- Make sure camp information and other official information is passed on

Change attitudes:

- Speak out on inequality: Most people with disabilities said that their faith community had never spoken out in support of people with disabilities;
- Make sure appropriate language is used; side with disabled people when they are being mistreated;
- Recognise and make use of disabled people's skills and knowledge so that others also realise disabled people's contribution to the community

Improve environment/advocate with them to get additional services:

- Lobby with disabled people for and/or help build ramps, bigger latrines; easier access to wells or rivers for water; meetings being held where disabled people can go and in a way that they can participate
- Lobby with disabled people for food provisions being delivered to disabled people who cannot leave their house/tent or cannot go to distribution places; volunteer to accompany disabled person or deliver to them
- Establish with disabled people protection systems for women and girls collecting fire wood, water, using toilets
- Lobby with disabled people/families for including disabled children in education including transport to schools; choosing sports and activities or adapting them so that children can participate

What might be the result of faith communities and people with disabilities and their carers working together?

- People with disabilities and their carers feel less vulnerable when they have set up a local protection committee
- People with disabilities and their carers feel less isolated when they have set up a local support network
- People with disabilities and their carers feel empowered to improve things when they are members of a disability committee in the camp
- Faith communities and the local community are enriched by the capacities of people with disabilities that they had not appreciated before, skills, gifts, cultural knowledge, experience
- People with disabilities feel less marginalised



Grouped housing for older people, Meheba refugee settlement, Zambia, photo: Anglican Alliance



Neema, from DRC, is active both in her church and in the wider community. She was elected as camp leader and is a member of the disability group in Kinama refugee camp in Burundi. While her arm deformity limits her in some ways, she can do most things and her enthusiasm opens doors for her. She was keen to work with the project after the workshop in Kinama camp.

Photo: Anglican Alliance

Community-based child protection committees as a model

Community-based child protection committees have been used successfully in many settings to protect children from abuse and exploitation. Trusted members of the community are elected to work with the children to identify the protection issues and find local solutions. The group engage with key community leaders and agencies to change attitudes and behaviours, to reduce stigma, and respond to and prevent abuse and exploitation of children. They also work with the community, particularly children to raise awareness of the children's right to be safe (protected). They can work as part of a national system of child protection, but also in unstable situation they may be supported by faith communities when national systems have broken down.

In many countries, Disability Committees exist within communities to ensure disabled people can voice their concerns and work with community leaders, faith leaders and local government officials to mainstream disability into community development programmes.

In camps for refugees and internally displaced people such Disability Committees are all the more important to ensure safety and appropriate support of disabled people. From your workshop and community engagement, you might set up a local disability committee, an example is shown in Annex 10.

It is important to include disabled people at any stage of any planning and implementation of interventions so as to not to make assumptions about their (dis)abilities but work together on the basis of lived experience and the trusted motto:

“Nothing About Us Without Us”



Chibwabwa has just been elected as treasurer of the management committee for the disabilities group in Meheba refugee settlement, Zambia. Despite being left with paralysis after a complex illness in 2008, she manages her home with the help of her children after her husband left. As well as a small business selling charcoal and oil, Chibwabwa is a skilled tailor, but lacks the capital to buy a sewing machine.

A tricycle to move about more easily and a sewing machine would allow her to be financially independent and use her skills. In addition, others would be able to enjoy the beautifully crafted clothes she can make.

She is a great role model for other people with disabilities. She was impressive when she challenged someone who said that disabled people could not be teachers. “I am lame, but I know and speak Swahili, I am a tailor. Does my disability mean that I cannot teach others?” While a man in a wheel chair explained being a teacher was a question of training and intelligence, not disability. He added that it is not against the law in Zambia for a person with disability to teach.



Drawing: World Health Organisation

A message from Bishop Eraste Bigirimana, founder of the Bethesda project in Burundi

Bethesda Project is a Christian, accessible, inclusive outdoor and outreach activity currently implemented in two Dioceses of the Anglican Church of Burundi namely Muyinga and Bujumbura Dioceses.

The ethos of Bethesda Project is founded on a commitment to bring disabled and non-disabled people together as equal partners. Many disabled people view their disability as only part of the disadvantage they must face. How society views that disability is often a much bigger problem to overcome.

The Project aims to address those issues by providing opportunities that promote the principles of inclusion. Disabled people use their own strengths and abilities to overcome physical and mental barriers. Challenging outdoor and outreach activities for disabled and non-disabled people develop social integration and breaks down prejudice and misunderstanding. Our motivation is to follow Jesus Christ's example to love each other as God has loved us and care for the poor and discriminated people.

In developing this resource in collaboration Anglican Alliance we wanted to know more about the situation of people with disability living in refugee camps and internal displaced camps and to engage with the next step of the project which is the sensitisation and involvement of all Church leaders to care for people living with disability.

In developing a team spirit, encouraging self-esteem and the appreciation of others, we hope to be a catalyst in tackling social exclusion and enable all to become part of solution within their own communities. It's hoped this approach will be of great value in the process of healing and reconciling our Communities and Nations.

We would like to end by expressing our gratitude and appreciation to Anglican Alliance for their support to and collaboration with us in producing this resource which we hope will be very helpful and inspiring to many Church leaders through the Anglican Communion.

Many thanks to DFID and to HIF for their support to our work.

May God bless you

Bishop Eraste Bigirimana
Founder of Bethesda Project

The Rt Rev. Eraste
Bishop of Bujumbura Diocese
Burundi



Be shepherds of God's flock that is under your care, watching over them—not because you must, but because you are willing, as God wants you to be; not pursuing dishonest gain, but eager to serve; not lording it over those entrusted to you, but being examples to the flock.

Christian text: 1 Peter 5:2-3

Annex 1

Why higher rates of disability are recorded

There have been many classification systems for disabilities over the years. The more traditional systems are based on a medical view of “disability”. A broader view of “disabilities” covers impairments, activity limitations, and participation restrictions, where:

1. An impairment is a problem in body function or structure, for example a cataract that stops light going into the eye so it cannot see shape and detail normally
2. An activity limitation is a difficulty a person has to do a task or action, such as is not able to read or move around
3. A participation restriction is a problem experienced by an individual in involvement in life situations, for example exclusion from school

This definition focuses on measuring difficulties and barriers (b and c) to participation caused by the impairment (a), rather than focussing on the medical impairment itself. It is based on the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organisation (WHO, 2001). As we want to see everyone disabled and non-disabled living life to the full, the tools in this resource use the ICF classification of disabilities to identify all people with disabilities that limit their daily activities and restrict their participation in community life.

It gives a much higher prevalence rate of disability than a system focussing on the medical impairment itself. The difference in prevalence rates between the two systems was noticed during community work in Zambia, where national statistics report 2% disability, against worldwide average reports of 15% using the ICF classification system.

A study in Zambia (Loeb et al 2008) also highlighted this. The study of 28,010 people used the ICF classification system to record the degree of difficulty people had in six areas (such as being able to see, to walk, to understand):

- 14.5% had some difficulty in at least 1 area
- 8.5% had a lot of difficulty in at least 1 area
- 2.4% were unable to do at all the activity in at least 1 area

This system identified not just the most severely disabled but also others who may need some provision to participate fully in daily life. With good health care, a well planned environment and a supportive community, these people may not feel that their disability limits or restricts daily life and that they can enjoy life to the full. However, this is not always the case. Many people have one or more impairments that together with community attitudes, a poor environment and inadequate healthcare mean that their daily life is severely restricted.

The tools in this resource (Annexes 12-14) use the ICF classification of disabilities to identify all people with disabilities. The tools and care profile also capture the variation in degree of impairment or limitation: none, a little (mild), a lot (which includes not being able to do an activity)(severe), to give a simple measure of the severity of the disabilities.

Two or more severe impairments or limitations would be considered a severe disability, while one severe impairments or limitations would be a moderate severe disability. These are the two categories that would be recorded by the agencies.

During field visits in Burundi and Zambia, it was clear that recorded disability levels were very low compared to those expected. This is because only the most severe and limiting disabilities are recorded by the authorities. The overwhelming response to profiling in Kinama refugee camp, Burundi, suggests that even severe and limiting disabilities are not all recorded. There was clearly felt to be unrecorded disabilities and a keen desire for increased support for people with disabilities and their carers.

This highlighted the need for community work to identify people with disabilities, who may be hidden at home and marginalised, not able to access support, even if severely disabled. Here drama was a good medium to raise awareness and change attitudes so that every person is valued and respected. A drama about a disabled boy hidden at home is given in the Annex 7a, together with notes on preparing dramas in Annex 7c.

Rights under the UN Convention on the Rights of People with Disabilities

The UN convention on the Rights of People with Disabilities gives the rights that people with disabilities should have to enjoy life to the full. The full agreement, the United Nations Convention on the Rights of Persons with Disabilities, is on the UN website at: www.un.org/disabilities/

Here is a list of the different articles of the convention:

Article 5 Equality and non-discrimination

Article 6 Women with disabilities

Article 7 Children with disabilities

Article 8 Awareness-raising

Article 9 Accessibility

Article 10 Right to life

Article 11 Situations of risk and humanitarian emergencies

Article 12 Equal recognition before the law

Article 13 Access to justice

Article 14 Liberty and security of person

Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment

Article 16 Freedom from exploitation, violence and abuse

Article 17 Protecting the integrity of the person

Article 18 Liberty of movement and nationality

Article 19 Living independently and being included in the community

Article 20 Personal mobility

Article 21 Freedom of expression and opinion, and access to information

Article 22 Respect for privacy

Article 23 Respect for home and the family

Article 24 Education

Article 25 Health

Article 26 Habilitation and rehabilitation

Article 27 Work and employment

Article 28 Adequate standard of living and social protection

Article 29 Participation in political and public life

Article 30 Participation in cultural life, recreation, leisure and sport

Annex 3

Some causes of impairments, possible prevention and ways to mitigate the impact of impairments

Causes of impairments - and results	Possible prevention	Mitigate impact
During pregnancy		Good antenatal care
Certain drugs, such as sulphonamides, in first 3 months – teratogenic conditions (birth defects)	Avoid use in first 3 months or use under medical advice	Strengthen awareness Use drugs only when prescribed by doctor
Drug abuse, cigarettes, alcohol – early birth	Avoid intake during pregnancy	Strengthen awareness
Severe infections/diseases e.g. measles – early birth, birth defects	Vaccination	Early treatment and rehabilitation
Repeated malaria – early birth, birth defects	Sleep under insecticide treated net every night during pregnancy	Strengthen awareness Early treatment of malaria in pregnancy
Mother's malnutrition – slow growth of the baby	Eat a good balanced diet	Strengthen awareness Nutritional support and micronutrient supplementation
Chronic foetal infections e.g. syphilis – deformities in the baby	Screen for syphilis during pregnancy	Early management of syphilis in pregnancy
During delivery		Good maternity care
Prolonged labour – hypoxia (lack of oxygen) - neurological problems (brain damage), mental retardation	Good antenatal care, planned delivery by skilled personnel for at risk mothers, delivery by skilled personnel	Access to equipped facilities for assisted delivery
Use of unsterile instruments during delivery – infections e.g. tetanus	Use sterile instruments and clean place of delivery Immunisation of mother	Good hygiene Clean place of delivery Tetanus immunisation during pregnancy
Children		
Malnutrition and anaemia – slow growth and mental retardation	Eat a good diet and micronutrient supplementation	Early treatment of illness (intestinal worms) Prioritise food for the most vulnerable Nutritional advice and support
Severe infections/diseases e.g. polio, meningitis, measles, river blindness – severe paralysis, deformities, epilepsy, deafness and blindness	Vaccination, sanitation and hygiene, good medical care	Early treatment and rehabilitation
Severe infections e.g. cerebral malaria – neurological disorders (brain damage)	Sleep under insecticide treated net	Early treatment
Accidents/physical trauma e.g. wounds, fractures - deformities	Care of children, teach about risks, take care	Quick medical care Rehabilitation

Causes of impairments - and results	Possible prevention	Mitigate impact
Adults		
Severe infections/diseases e.g. polio, meningitis, measles, river blindness – severe paralysis, epilepsy, deafness and blindness	Vaccination, sanitation and hygiene	Early treatment and rehabilitation
Accidents/physical trauma e.g. wounds, fractures, deformities , including from war and conflict	Understand and avoid risks, take care	First aid training, good safety policies/ standards Quick medical care Rehabilitation
Neurological diseases e.g. epilepsy	None	Good long term medication Protection from injury during seizures
Lifestyle related diseases e.g. diabetes, hypertension (high blood pressure)	Exercise and eat a good diet	Body weight control Good medical care Rehabilitation
Drug abuse, alcohol abuse - alcoholism, drug addiction	Control and counsel	Rehabilitation and supportive environment
Mental trauma e.g. depression, anxiety, including from conflict, abuse, stress	Stable environment and good social relationships, avoid abuse, stress, conflict	Psychological treatment Psychosocial support Stable environment Good social relationships
Old people		
Malnutrition and anaemia – weakness, risk of falls	Eat a good diet and micronutrient supplementation	Prioritise food for the most vulnerable Nutritional advice and support
Physical/skeletal conditions e.g. arthritis, osteoporosis, fractures	Eat a good diet, maintain gentle activity	Good health care Rehabilitation Psychosocial support
Mental conditions e.g. dementia, forgetfulness, depression	Eat a good diet	Good health care Psychosocial support

Annex 4

Example of agenda for a workshop using the resource

1. Welcome and introductions
2. Opening prayers
3. Spiritual devotion/bible study
4. Expectations
5. Objectives
6. Scenario or drama to introduce issues of disability
7. Introduction to disabilities,
 - a. Overview
 - b. Rights
 - c. Types
 - d. Causes, prevention and mitigating impact
8. Impact of disabilities
 - a. General
 - b. Social and physical barriers
 - c. Disasters and emergencies
9. Children of God
 - a. Everyone is valued and loved
 - b. Gifts and capacities
10. What faith communities can do
 - a. Welcome and care
 - b. Learn about disabilities
 - c. Learn about people with disabilities locally and their situation:
 - Identification
 - Profiling
 - d. Support people with disabilities and raising their voices:
 - Care profile
 - Advocacy
 - Protection
11. Planning the next steps

Annex 5

Example from Burundi of how local faith communities used their religious texts to reflect on issues of disability and “a better life together”.

Some bible studies ideas on “a better life together” :

Here are four linked bible studies on the general theme: The Body of Christ, to help us to remember that each one of us, disabled or not disabled, needs to listen to God and learn from God.

1. Looking at who we are in God’s eyes; we are special, valued and chosen by God, key work chosen (to be in the Body of Christ)

Whether we have a disability or not we need to understand that we are special, valued and chosen by God before we can accept that we are part of the body of Christ. This Bible Study reminds us that God sees us, not as disabled or useless but as precious and valued.

Suggested texts: 1 Samuel 16: 7; 2 Sam. 4:4, 9:1-13; Isaiah 43:1; Ephesians 4: 11-13; Luke 18: 35-43; Matthew 7: 12

2. Looking at the Body of Christ (us) working together, key word valued (in order to serve)

Each person has a part to play in God’s work here on earth. We are all parts of God’s body with a job to do, whether able bodied or disabled. In fact, those with disabilities can have special gifts which we particularly value.

Suggested texts: 1 Corinthians 7: 7b; 1 Corinthians 12: 12 and 20-27; 1 Peter 2: 17a; 1 Peter 4: 8

3. Looking at the Body of Christ (us) serving one another, key word united (to show the Fruits)

Service to others is important in our Christian life. Whether disabled or able bodied we can serve others. Christ gave himself to us as a servant; we should do like Christ and be willing to serve all people, whatever their situation. In order to do this we need to be united in purpose.

Suggested texts: 1Corinthians 10: 24; Galatians 5: 22-23; Galatians 6: 2; James 2: 14-17; James 2: 26

4. Looking at how we, the Body of Christ, are united by love, compassion and mercy to do Christ’s work here on earth, key word disciples (sent out in Christ’s name)

The aim of this study is to see how the Bible shows us the importance of justice, mercy and compassion, but the most important gift is love. If we follow the teaching in these verses we will all go out as the Disciples of Christ.

Suggested texts: 1 Corinthians 13; Ephesians 5: 1-2; Matthew 7: 12; Micah 6: 8; Zechariah 7: 9-10

Note: Other faith leaders and communities may work with their own texts to reflect on their faith guidance on issues of disability and “a better life together”.

Scenarios to introduce disability issues

These can be prepared as a drama for a meeting or for raising awareness of disability issues in the community.

Scenario One

“Emmanuel, are you coming to school?” shouted Reverian “Today we will learn about things in science!” Emmanuel looked angry. Why did Reverian bother to ask? Of course he wasn’t going to school; he never had gone to school, and as far as he could think he never would go to school. When he was 3 years old he had been very ill with meningitis, and although he recovered well he could not see anymore. Here at the camp no-one had asked his parents about him, no-one in authority had mentioned him. He began to wonder, had his parents even registered him? If he wasn’t registered at the camp then he didn’t exist, did he? He was only a child, how could he ask his parents such a question? These thoughts went round and round his head.

Scenario Two

Water! No-one can live without water can they? Mama Flora looked at the empty water carriers and pot and went in search of her firstborn, Flora. Flora had wandered off again just when she needed her. She loved Flora despite her slow mind and strange ways. Since birth she had never been like other children, and now at 18 years old she was beautiful but with the mind of a small child. Mama Flora relied on her daughter to help her collect water, especially as the water point was far from their house. She would be able to send Flora on her own to collect water if it had been nearby but it was dangerous to send her far away. Oh she had seen the look in the eyes of some of the men when Flora walked past them, a look that put fear into Mama Flora’s heart. No! She would always have to accompany her daughter to collect water.

Scenario Three

Fabian sighed heavily. He was thankful that he had been able to arrive safely with his parents at the refugee camp and he knew he should be grateful for the shelter and food that they were receiving, but there were some things that seemed so difficult. He had grown to be a strong 16 year old, and despite the fact he could not walk but could only crawl, he felt normal in every other way. But oh, the embarrassment when he went to the toilet. Crawling in to the place where others had squatted, putting his hands on a floor that was dirty, and he felt sure people looked at him with shame and pity when he came out. How he longed for an appropriate toilet. He sighed deeply once again.

Scenario Four

Once again Immaculata prepared herself to join the queue at the food distribution point. Three of her children were safely at school and her youngest child was firmly tied to her back; getting heavier now as he was 1 year old. She gathered her straw bag and cloths together, and her carrying pad so she could bring the supplies to her temporary home. It was a long walk to the distribution point, but she was fairly fit, and as she walked she thought about all that had happened, her husband being murdered, her left arm severed at the elbow, and her escape with the children. They were her hope now. As she arrived at the distribution point she noticed that cooking oil was being given out today, as well as a sack of flour and various other items. Now the challenge began. How was she to pack and carry everything with only one hand? Yes she would carry on her head of course, but packing, tying up in the cloth and lifting on to her head was hard. Immaculata faced the challenge but wished for an easier answer that wouldn't exhaust her so much.

Scenario Five

The house was rather small for 8 members of the family but somehow they all fitted in. After all, it was a safe roof over their heads, and food was supplied for them. "Perhaps there is not always enough food" thought Maria, "but no-one really goes hungry. When food is in short supply I give less to John; perhaps even miss him out altogether. But that doesn't matter, he is unable to understand or speak so it is better to give food to the children who are at school." These were Maria's thoughts as she cooked the evening meal. Life was hard and Maria struggled to make the food last till the next distribution. "John does look a bit pale and he has a bad cough" she thought "but what can I do?"

Scenario Six

Adventina had five children, 3 girls and 2 boys. Were they all a gift from God? She wasn't sure. Her fourth child, Gabriel, had a shocking split to his mouth, all the top of his mouth and even the roof of his mouth were gaping holes. Oh the shock when he was born! Oh the shame! Adventina had been a regular member of her church but when Gabriel was born she was afraid to go anymore. Someone had said to her "You know why Gabriel was born like that don't you? You used your mouth for filthy words and lies. It is God's punishment." Ever since that day she had not attended church. How could she? She sent her children to Sunday School, but they were teased sometimes, and came home upset. No, she felt she could no longer attend church.

Annex 7a

Drama 1: The parents hide their disabled child

INTRODUCTION: This play is about a family who give birth to a disabled child. The child was kept hidden by the parents. However the parents receive a visit from someone who gives them advice about disability. The guest gives this advice: "I also had a child with a disability like your child but I took my child to hospital, and the doctor operated and he got much better. I registered him at school, and now he is the head of the District Council!" After receiving this advice the parents planned to take their child to hospital where she/he could be treated by a specialist doctor. The parents also took her/him to be registered at school and now she/he is doing very well.

OBJECTIVE: The objective of this drama is to advise parents who have a disabled child that they should look after their child well and not hide their child because he/she has a disability. The drama advises that a child with a disability may be able to improve their life with treatment and should have the chance to go to school.

SETTING THE SCENE:

Mother and father are sitting in their house. Their disabled child is sitting in the corner. Mother gives the child a plate with some food and is sent away to eat separately from the family. Because the child can only use one hand the plate slips and the child cannot feed herself/himself. When the parents hear a 'hodi' outside they quickly run to hide their child. ('Hodi', Swahili greeting like hello, called when knocking on someone's door)

THE PLAY

NEIGHBOUR: 'Hodi, hodi!' Where have they gone? (Shouts) Where are you? Hodi!

MAMA: (Hurries outside) Welcome, welcome.

NEIGHBOUR: I'm sorry, are you eating?

FATHER: (Speaks strongly to his wife) Hide that disabled child quickly. Don't let the visitor find her/him here. Didn't I tell you not to let anyone find the child here? You don't listen to me.

MAMA (Whispers urgently to her child) Go in that room, go away and be quiet. (Calls out to the visitor) Yes, welcome, we are here! Truly we have missed seeing you.

NEIGHBOUR: The work of planting has taken all my time so I had no time to visit.

FATHER: Truly we were just asking ourselves where you had gone because we had not seen you. My wife had just been saying we should visit you at your home.

NEIGHBOUR: How are you all since I last saw you?

MOTHER: Very well indeed.

NEIGHBOUR: Yooo, where is your child? Bring him/her to me. Really I desire so much to see him/her and to greet him/her.

MOTHER: Uuuuh! All the children are at school.

NEIGHBOUR: What is the time? Have they not yet come home from school? And the youngest, is she/he at school? It's a long time and we've not seen the child, he/she must have grown.

FATHER: No, no, we are talking about the other children. That one is not a child.

MOTHER: Truly I have given birth to children but now my work is not giving birth but to break my back.

NEIGHBOUR: Uuuh, that is true; but I cannot go without seeing with my own eyes your son/daughter. It was to see him/her that really brought me here!

FATHER: My friend, let me bring you that strange child so that you can laugh.
(Father drags the child by the arm, the child limps over and sits on the floor.)

NEIGHBOUR: Yooooooooo, really this is terrible, he/she is dirty, not like the other children who are clean. Truly he/she smells bad. Take this child away.

CARING VISITOR: Hodi, hodi friends who live here. I was passing and thought I couldn't pass without greeting you. Oh but this child of yours, you are not taking care of him/her well. If you help him/her then she/he can help others. Remember my child? He was like your child, but I took him to hospital and they helped him with treatment, he improved and then I registered him at school and do you know he is now head of the District Council!

NEIGHBOUR: (In a surprised voice) Do you mean that Head of the Council whom everyone likes?
(From this point onwards the child listens to the conversation and reacts in appropriate ways.)

FATHER: That one! Oh yes, he leads us well! What are you saying? Truly I was asking myself how you can live so well; you have good clothes, a good house....really I was surprised especially since your husband has died. And I can't even manage to build a good house! I am surprised, do you mean a disabled person can be intelligent like other people? They can help improve their family's life? (He turns to speak to his wife) Dear wife, we should decide to help our child. Have you heard what this good visitor is telling us? It is us who have made the life of our child so bad. Yule

GOOD VISITOR: Eeeh, now you must try hard to help your child, take him/her to hospital to see if they can help him/her. Feed your child well with good food and let him/her eat with the family. And don't forget to register your child at school. You wait, you will see much improvement.

MOTHER: Is it true that a disabled person can grow and bring improvement if she/he is helped? And then they can help others in this country of ours! Ha ha ha I will be close to my child, I won't hide him/her any more. If God gave me this child then he has a plan for us. Come husband, let's go and register our son/daughter for school!

NEIGHBOUR: And I will come with you! Let's go!
(They all hurry off to school leaving the child clapping his/her hands in excitement and saying excited things like "I'm going to school. I shall have new clothes! I can play with other children! Oh I am so happy")

Annex 7b

Drama 1: The Albino child

OVERVIEW: This drama is about a family who give birth to an albino child. The father of the child says the child is not his child because the child is a white child, the child of a white father. Some people living nearby say to the father that he will become rich because he has something of great value at home. Fortunately one neighbour calls at the house and sees the problem at home and explains to the father about albino children and the father understands. Now see the play for yourself!

THE PLAY

Albino child and his/her sister: The two children are playing together and chatting

FATHER: (In an angry voice speaking to the sister/brother) I have told you many times you are NOT to play with that child. We do not know where that child came from. (Emphasise 'that child')

BROTHER/SISTER: (Speaks to the albino sister) Don't worry, we'll play when father goes away

ALBINO CHILD: (Crying and runs to mother) Ohhhhhh mother. Father refuses to let me play
Mother comforts her child and sends the albino child and his/her sister to collect water from the pipe.

FATHER: (In anger) Wife, have I not told you time and time again, since long ago ; that child has no-one that resembles her/him in our community.

MOTHER: It's true, I was shocked when he/she was born. But if God chose to give us this child, then we should thank Him.

FATHER: (In anger) Truly, you know when people see me they laugh at me. And the questions they ask me! Terrible questions and I cannot reply to them. And others tell me I have a very valuable package at home, worth a lot of money!

MOTHER: (in a shocked voice) What are you saying, that a child is worth a lot of money? What do you mean?

FATHER: Eh, people say things, they laugh and say that I have a very valuable package at home. They say one day they will come and kill us and take the child. Quickly, leave here with the child, I don't want you here, leave quickly, quickly.

MOTHER: (In bewilderment.) Husband of mine, where can I take this child of yours?

FATHER: (Losing temper) Truly this child is NOT my child. Take the child to his/her father. Everyone knows the child is not like any other child of mine. It's NOT MY CHILD! (Shouting)

MOTHER: (In tears) Oh my husband, don't accuse me of such things. Truly I have not done such a thing against you.

FATHER: Am I accusing you? Tell me the truth about where you have been. Remember you told me you were taking avocado to market to sell. Did I not see you with my own eyes? you were with that white man, one who works on building the road. Maybe you did more than sell avocado?

The children return from collecting water. They meet with 2 neighbours in the road.

NEIGHBOUR 1: You, aren't you the child who lives nearby?

NEIGHBOUR 2: (Laughs) Ha ha ha, it's not a neighbour's child. Since when can an African neighbour give birth to a white child? I have heard, and it must be true, that his wife slept with a white man who is building the road.

NEIGHBOUR 1: Maybe that's true. I had thought that to give birth to a child like that must be the result of great sin that the parents (she and her husband) did when she was pregnant. (In a voice of panic) Oh look, they are coming to speak with us, quick let's go before we too become infected with this terrible thing.

ALBINO CHILD: (In a happy voice of a child) Hello, hello..... (begins to say something else but is interrupted)

NEIGHBOURS: (In a loud voice and in panic) Go away, go away quickly, we don't want you near us, go away, you might infect us and then we will give birth to children that are not normal !

ALBINO CHILD: (She runs off crying with her sister/brother also crying, and reaches home) Ohhhhh mother, mother, they laughed at me so much and said bad things about me.

FATHER: (Raises his voice at the children) Eh eh eh stop making such a dreadful noise. It is all your mother's fault. (Father loses his temper, shouting and begins to beat his wife) DO YOU HEAR WIFE, THIS NOISE I WILL NOT ALLOW, I WILL SHOW YOU HOW TO BEHAVE, I WILL SHOW YOU... (he beats her) Go away from here you white child, go to where you belong, to your place.

The children are frightened and hide behind their mother

A GOOD NEIGHBOUR : She calls from outside the house). Good morning to you my neighbours ! Oh, listen to the noise, they are fighting each other!! (She goes in to the family compound and sees the husband hitting the wife. She cries out) Oh truly they are fighting badly .

FATHER: (In anger) Oh you, my neighbour, what have you come for? To laugh at me?

GOOD NEIGHBOUR: (in shocked voice) No no, you parents, stop doing such a terrible thing.

FATHER: (In anger) You have come to make rules in our house and tell us what to do? I'll show you what we do.

GOOD NEIGHBOUR: (In a firm strong voice) It's not that I am telling you what to do but please stop hitting your wife, is not true you will kill someone this way?

MOTHER: (Almost in tears; with relief in her voice.) Oh thank you Mama, if you had not arrived he would have killed me. Truly I think that this is a punishment given to me from God. Listen to what he is saying, that this child of mine is a white child from the man that works on building the road. Please, you have been my neighbour for many years, have you ever seen me with such behaviour as he is accusing me of?

GOOD NEIGHBOUR: (To the father) Stop it, stop it! You should not be doing such a terrible thing. Is it really the first time you have seen a child like your son/daughter?

FATHER: You mean to ask if I have seen a white person? Oh yes, I have seen a white person with my own eyes. Look at the child's hair how it is like a white person's hair. Truly this child is a worthless white child.

GOOD NEIGHBOUR : No, the parent of your child is not a white person, although you refuse to admit he/she is your child. Your child is what they call Albino. It can happen in many families. Look back at your grandparents or their parents or grandparents, maybe there was an albino child born back in your ancestors? So stop causing so many problems in your home, your child is a child like any other child. Now quieten down.

FATHER : (Looks very thoughtful) Wait a minute Mama, you say in my ancestors? Truly Mama, I remember my grandfather once told me that his grandfather had an albino child. Ohhhh, if you had not told me I would have murdered my dear wife, and my child too!

GOOD NEIGHBOUR : Oh my! So what we need to do is to let people know that an albino child, or any child with a disability is like any other child. (Pointing to the father's albino child) Now your child needs to wear a hat, dark glasses, clothes that will cover up her/his arms and legs and use cream to keep her/his skin soft. Children who are albino need to be protected from the sun. What is very important: you must register your child for school so she/he can learn like other children. You know albino is a problem of the skin, not the brain. Your child has a normal brain.

FATHER: (Speaks to the child) Let me give you my hat to protect your head from the sun, and my glasses to keep your eyes from hurting. My coat is too big, but you can wear it for now. Mother, do you have some cream? Put some on our child!

ALBINO CHILD: (To her sister) Oh did you hear that? I can go to school, I can go to school! Oh I am so excited! Let's go and play now.

How to create a drama

INTRODUCTION: Drama is a good way of raising awareness of issues in a lively entertaining way. It is very effective as it is accessible to all ages and all groups. As drama is such an effective way of engaging people and changing attitudes, it can also be used for advocacy. You can use it to bring about changes to the local problems that are identified during the advocacy exercise in Annex 8.

If you are using drama for advocacy, it is good to relate the problem to the rights of people with disabilities in the UN convention (Annex 2). This is important as it brings to focus to the rights that people with disabilities have like other people to live a good life free of fear and discrimination.

TO BEGIN WITH...

- Firstly ask your group to think carefully about the subject of the drama. Ask yourselves this question: What is our subject for the drama? It might be about including people with disability in community meetings. It might be about disabled children getting access to school. Make it a general problem that your group will relate to and don't use a specific case locally.
- When you have decided on the subject of the drama ask the following question: What are the 3 main points that we want the audience to understand? (It may be less than 3 points; usually it should not be more than 3 points) By asking this question you will FOCUS your drama clearly
- Then ask this question: What is it that I want the audience to understand at the end? This links in with the 3 main points; in what way would you like the audience to change their behaviour as a result of watching the drama? You want the audience to feel the injustice of the situation. The more angry people become, the more they will want to participate and try to change things.
- Now comes the fun bit.....together as a group create a story where the 3 points are clearly included. When creating a story use all your imagination, experience and ideas and bring them together in a short story. Why short? Because when you perform it, it will be much longer than you had thought!
- When you have some of the ideas (not necessarily all of them) begin to think about which person might be good for which parts; this is the casting of the parts. You may have some natural parts
- Now write some notes about the play so that you have a 'skeleton' outline from which you can begin to practise
- Even at this early stage you can begin to 'walk through' or try out your ideas in a play form. This is only trials, and you can read parts, put in your own words etc but do not lose focus of the 3 points.
- As you continue practising you may need to change the casting; don't be afraid to do this if necessary. The whole aim of the drama is to bring to life a situation that needs changing in the community
- After some more rehearsals ask someone you trust to watch the drama and advise you of anything that could be improved

NOW ABOUT THE WAY YOU ACT:

- Speak slowly (but not too slowly!)
- Speak clearly making sure your voice reaches the very back of the place where you are performing
- Remember if you are outside, the wind might take the sound away so take extra care when performing outside.
- Remember to use different levels of voice, both pitch and volume
- Your actions must be slower than in normal life (but not too slow) and clear. Always remember where the audience is. Beware of having your back or even side to the audience; think to yourself “Can the audience see what I am doing?” And don’t hide someone else from where you are standing unless that is part of the play
- It is very important that you communicate with the audience; read their reactions. Remember that if the audience laugh then they have listened!
- Try to avoid adding lots more words to your part, making it too long. The play is to teach the community and not become famous

COSTUMES

Keep it simple; just enough to create the part. Use local resources

And most of all ENJOY YOURSELVES!

Sharing the drama more widely

Once you have done one drama, encourage others to have a go too. After seeing your drama, the Sunday school or youth might want to do one too. They can then take it to school and do it there. In this way, the message is spread in the community, as people will be talking about the drama at home, at the water point, at the shops. Listen to the reactions and take account of them when you prepare your next drama. This is especially important if you think people have misunderstood the message.

Advocacy exercise

This exercise will help you to:

- Identify local problems for people with disabilities
- Plan the advocacy that is needed by working on the most important issues
- Decide the change that you want to see related to those most important issues
- Work out for each issue: what needs to happen to get the change

As you prepare for the exercise, be aware of different difficulties and plan to include everyone, for example use pictures instead of words so people who are illiterate, speak different languages or have learning difficulties can fully participate. Think about how you include people who are blind or deaf.

1. Identifying local problems for people with disabilities

- Ask each person to choose (and write down) what they think is the main problem for people with disabilities here
- Ask people to share what they have chosen (write down or collect the pieces of paper)
- Group together similar problems and record a statement that describes them: your problem statements
- Ask each person to mark which they think is the most important problem, and also the second most important (with a different colour or symbol)

In Groups:

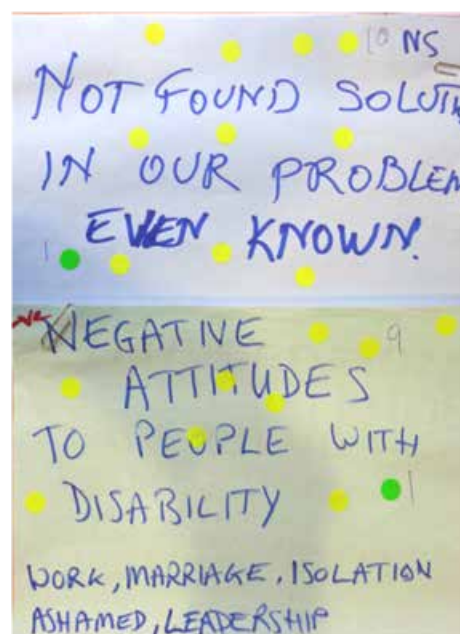
Divide people into groups, making sure that each group includes people with disabilities. Select the top priority problems (the ones with most marks) and give one to each group. Ask them to work through the following questions in relation to that problem.

2. What is the change that we want to see?

Each group discusses the change that is needed to allow people with disabilities to fully participate in daily life, to feel respected and treated as any other family/community member, in relation to that problem they have been given. Write these down, your change statements.

3. What can we change ourselves? How?

Discuss and write down what you (as individual, faith communities, local communities etc.) can do to make the change happen. What can you do that would make life better for people with disabilities here?



Top priorities in Meheba refugee settlement, Zambia for people with disabilities

Discuss and write down how you can make the change happen for each of the things that you have identified.

4. What can you influence others to change? Who?

Discuss and write down what you need to influence others to change. What are the bigger issues that you cannot change alone, but that you can advocate to others to change?

Discuss and write down who (the people or organisations) you need to influence for each of the things that you have identified.

5. What will persuade them?

Discuss and write down what might persuade them to support your point of view. Do they need a report on the situation with detail of the problem and the solution that you propose? Do they need records of the numbers of people affected and needing this change? Do they need letters from the people affected? Think what you need for each different issue that you are advocating for.

6. Who else do we need to support us?

Discuss and write down who else is affected by the problem you are advocating about, who else might care about the situation and support you (this might be locally or from outside). The more people work together, the stronger the impact will be.

7. Next steps: action plan

You have identified the changes you wanted to see, both things that you can do yourselves and things that you need to influence others to change. Now plan what is needed to take this forward. Make a chart:

Change	How	Who	When

- Fill the chart with detail about the things that you can change, how you will do it and who will be involved
- Then put the things that you will need to influence others to change, how you will do it and who will be involved
- Also put in who you will need to get to support you, how you will do it and who will be involved
- Now look at the list and decide which change you will start with and add to each line when you plan to achieve the change

This will look like a big task, but by writing it down you will have a plan for the steps that will allow you to achieve a lot. By working together to a plan you can achieve more than you think possible.

8. Share your discussions with the other groups

Protection exercise

This exercise will help you to identify the kinds of abuse and behaviour that can cause harm to people with disabilities and to think about the kinds of people who do this and the effect this has on people with disabilities. You will then be able to plan what needs to be put in place to protect people with disabilities from abuse and harmful behaviour.

Our thoughts about people with disabilities and abuse are determined by our own personal experience of people with disabilities in our families and communities, but also by our work, culture, religion and current situation.

It is important to remember that people with disabilities are individuals with rights just like all of us. They need shelter, food and warmth, but they also need love and respect. People with disabilities can be vulnerable but also have strength and resilience.

This exercise will help you to:

- Identify the kinds of abuse and behaviour that affect people with disabilities here
- Identify the actions that can be taken by the family and the community to protect people with disabilities, to prevent abuse
- Identify the support that can be given to survivors of abuse, including who to report it to

As you prepare for the exercise, be aware of different difficulties and plan to include everyone, for example use pictures instead of words so people who are illiterate, speak different languages or have learning difficulties can fully participate. Think about how you include people who are blind or deaf.

1. What kinds of abuse and behaviour can cause harm to people with disabilities?
2. What kinds of people do this?
3. Is this linked to traditional belief?
4. How does it affect people with disabilities?
5. Are there any laws that exist to protect people with disabilities?
6. What actions can be taken by the family and the community to protect people with disabilities?
7. Who should incidents of abuse of people with disabilities be reported to?
8. Next steps: action plan

Here is a check list, for the leader of this exercise of kinds of abuse and behaviour that can harm people with disabilities:

- Physical abuse
- Sexual abuse
- Emotional abuse
- Neglect and negligent treatment
- Sexual and commercial exploitation
- Abuse of human rights of people with disabilities

Annex 10

An example of setting up a disabilities committee and developing an action plan

Here is an example of setting up a disabilities committee and developing an action plan, from Meheba refugee settlement, Zambia

At the end of the workshop in Meheba refugee settlement, Zambia, that helped develop this resource pack, participants agreed to form a disabilities committee to progress activities. They decided that the committee would have 7 members selected from the workshop participants. Care was taken to include people with disabilities, women and men, different faiths or denominations and a range of ages.

- Chairman
- Vice Chairman
- Secretary
- Vice secretary
- Treasurer
- and 2 general committee members

Developing an action plan to progress activities

Participants developed an action plan to plan how they would better support people with disabilities in the refugee camp/settlement. This version is rearranged and expanded with more detail, to make it easier for someone who was not at the meeting to understand.

Action plan

	Activity	Resource	Time	Responsible person
1	Formation of disability committee		Today	Chairman
2	Register all members		Today	Committee
3	Meeting to identify tasks and develop a workplan including objectives, identifying and meeting key authorities and agencies		During next week	Committee
4	Create a register of regional and national disability organisations		During next month	Committee
5	Training community volunteers		During next week	Committee
6	Create a register for all people with disabilities		During next 1-2 months	Committee
7	Categorise the type of disabilities and group		During next 1-2 months	Committee
8	Identification of skills within people with disabilities		During next 1-2 months	Committee
9	Hold meetings with people with disabilities to prioritise needs		At end of month 2	Committee
10	Create linkages with regional office	Records	At beginning of month 3	Committee & ZAC
11	Hold stakeholder meeting		To be decided	Committee & ZAC
12	Collect contributions to allow registration as an association and opening of a bank account		By beginning of month 3	Committee
13	Develop a constitution		By beginning of month 3	Secretary
14	Register group as an association, with constitution and collected registration fee	Registration fee	At beginning of month 3	Secretary
15	Open a bank account, with collected funds	Minimum deposit amount	At beginning of month 3	Treasurer
16	Develop relationships with relevant regional and national disability organisations		After beginning of month 3	Committee

Annex 11

Planning community engagement and training community based volunteers

Planning community engagement

Community engagement should be planned and coordinated to ensure a positive response from the community and camp authorities. It will usually follow a workshop about disabilities (example agenda Annex 4) and would be the faith communities' response to this. The most effective way to plan and coordinate community engagement is by setting up a disability committee to oversee this, see Annex 10.

Here are some things for the disability committee to do before community engagement:

- Discuss how information will be used and stored, including what will be shared with who. It is important to decide for example if you will be sharing the summary data of how many people have different disabilities (for example how many blind) with camp authorities, or details about particular people (for example to advocate for them for access to school or medical treatment).
- Find out how to refer people on to other services, such as support for Gender Based Violence (GBV). Set up a small group from the disability committee who community based volunteers can come to if they meet someone who has/may have suffered abuse.
- Select people as community based volunteers - people need to really understand and be sensitive to the issues that affect people with disabilities. At least one of the pair visiting each home should be able to read and write the language of the questionnaires. If people are very sensitive, then particular care should be taken with who visits.
- Train community based volunteers, see guidance below
- Organise community meetings to raise awareness of the disability committee and the work it will do in the community before any community work starts
- Meet with camp authorities to share plans for community engagement
- Coordinate visits of community based volunteers
- Prepare ID for community based volunteers

The purpose of the community engagement is to allow you to identify and profile people with disability (tools in Annexes 12 and 13), to be able to prepare care profiles for them as shown here (Annex 14). Through this process you will learn about the key issues faced by people with disabilities in your context. This will allow you to plan further activities, particularly relating to advocacy and protection (Annexes 8, 9, 15 and 16)

The following things will need to be done once the community engagement has been started

- Safely store information from identification and profiling questionnaires and care profiles
- Create a register of people with disabilities
- Look at the information, sort and group the types of disability to get data for advocacy
- Organise meetings in community to share information; this will also be a good opportunity to raise awareness of disabilities and their impact on people living in this context using drama (Annex 7)
- Organise meetings with people with disabilities to plan further activities



Training of community based volunteers

To be effective community based volunteers need training before working in the community. They should already have taken part in a workshop about disability, so that they know what the community engagement is about. Here are some of the things that should be covered in the training:

- **What are disabilities?**

‘Disabilities’ is a broad term that covers impairments, activity limitations, and participation restrictions.

1. An impairment is a problem in body function or structure, for example a cataract that stops light going into the eye so it cannot see shape and detail normally
2. An activity limitation is a difficulty a person has to do a task or action, such as is not able to read or move around
3. A participation restriction is a problem experienced by an individual in involvement in life situations, for example exclusion from school

This definition focuses on measuring difficulties and barriers (b and c) to participation caused by the impairment (a), rather than focussing on the medical impairment itself.

It is important also to be clear that not all disabilities are visible, the range of disabilities includes mental illnesses like depression and severe anxiety, which can also prevent people from participating fully in daily life.

- **The purpose of the community engagement and expectations**

Community based volunteers need to be clear why they are visiting and asking questions, as people will want to know why they are coming round asking things and how the information will be used (see below). The community engagement is for faith communities to:

- Identify people with disabilities in the community, even the hidden ones
- Learn more about each person with disabilities to prepare a care profile for them
- Learn generally about people with disabilities here and their situation, so as to
- Be able to engage with and support people with disabilities better, particularly through advocacy and protection of the vulnerable

It needs to be made clear at the start of each interview that there are no funds to give direct help. The faith groups are looking to improve the quality of life for people with disabilities by changing attitudes that stop people with disabilities participating fully in family and community life. They will work with people with disabilities and their families to prioritise the needs and advocate for changes. They will particularly look to protect the most vulnerable. We see all people disabled or non-disabled are made in the Image of God, to be valued equally and believe the life is better when all participate fully in family and community life.

- **What information will be collected and how will it be used?**

Go through the identification and profiling tools in detail during the training, so that the community based volunteers know what information is being collected. Share with them what the disability committee decided about using and storing the information and who it will be shared with. It is important to be able to say what will happen to the information that people share.

- **Confidentiality, trust and consent**

People will be sharing very personal information in the interviews. It is important that they know they can trust the community based volunteers and the disability committee. Community based volunteers should not talk about the people they have visited or their situation. What is said should be confidential. This is important; otherwise people will not share their personal information and their situation. If the confidentiality and trust are broken, then further work

will be very difficult. People need to know how the information will be used and stored and if it will be shared, what will be shared and with whom. This should be decided by the disability committee before the training and shared at the beginning of each visit. If people are happy, then they should sign/put a mark to show they understand. For children, or people who are not able to agree themselves, then the parent(s) or carer should sign/put their mark, if they agree.

- **Language**

It is important for one of the pair visiting a home to be able to read and write the language of the forms, generally it is better to talk in a language that the person you are visiting is happy with. They will feel more comfortable and will respond better to the questions. This will not always be possible and sometimes a second language or an interpreter will be needed.

- **Be sensitive**

Some of the questions, particularly those relating to the journey to the camp or if they have suffered abuse, may be upsetting for people. Community based volunteers should be sensitive, as remembering and talking about events may be difficult and cause distress. They should explain at the beginning of a visit that the person can stop at any time, and they don't have to answer a question if they don't want to. During a visit, be gentle and sensitive to the person you are talking to. If you think someone has suffered abuse, listen and record this if they want to talk; if not make a note and talk to one of the people from the small group set up by the disability committee for this. It is important to know if people are suffering harm and need protection, but do not probe, just listen if the person wants to talk. See case study at end of notes.

- **Understand what you are asking**

It is important to understand what is in the identification and profiling tool before going to someone's home. An important part of the training is to go through the forms slowly, explaining the questions, particularly where people think there is repetition. Then practise using the forms in groups using role play: have two people as the community based volunteers and two as the householder and person with disabilities. Try out the questions, then swap roles. If there is anything that is not clear, share it with the group, so that everyone understands it. This is an important part of the training, as some questions may seem to be the same, but are slightly different and this may not be clear with translation.

- **Visiting and when to visit**

Community based volunteers should visit in pairs to ensure that they and those being visited feel safe. This is to protect each of you from the risk for false accusation. Generally it is good to have a man and a woman in each pair. However, in your context, you might decide that two women should visit a woman who is on her own. Or in some cases it might be better to have two men visit a man who is disturbed. In your context, you may decide that you also need to be sensitive to particular issues such as country of origin, race, tribe, clan, faith group, age as well as gender. Certainly in those situations outsiders may not be welcome on the team.

Try to visit when people are not too busy, then they are more likely to be welcoming. Particularly for the profiling visit, which will take longer, arrange a time, day and place to talk beforehand. Then the interview will be more likely to be successful. This respectful attitude also establishes trust and allows the person to choose a safe time and place to be comfortable to talk. This is important if they want to talk about sensitive issues.

At the start of the visit, introduce yourselves as community based volunteers; explain the purpose of the visit (why you are asking the questions), how the information will be used (to prepare a care profile for them, but also to learn about key issues for people with disabilities here to be able to support them better) and how long the visit will take. For the profiling, the person with disabilities should answer the questions. If this is not possible then someone else can help. If the person is

happy to answer the questions and share information, ask them to confirm this by signing/mark the form. If you want to take photos or use the story more widely, explain this and ask if they are happy with this and again ask them to sign/mark the form.

- **Identification**

Prepare identification (ID) for community based volunteers before they visit homes. Share details of this with the community when you talk about the community engagement. This will ensure that the work is understood and the community based volunteers are welcomed. This will help to gain the trust of the people and to reassure them that the information collected is for community support and will not be passed on to other organisations, for example to aid in forcible repatriation efforts.

The tools:

The identification tool is used to go from house to house, through gentle conversation to see if there is anyone in the household with disabilities, especially looking out for the hidden ones. The identification visit should be quite short so you can visit many households to identify those with people with disabilities. Remember that the focus of the visit is people with disabilities so try and capture these aspects of difficulties getting to the camp or living here. If someone with disabilities is identified through the questions in Section 1, continue with the questions in Section 2, for each person with disabilities in the household (using extra forms as needed).

Once people with disabilities have been identified, arrange to go back and talk in more detail about the situation of the person or persons with disabilities in the household, using the profiling tool, one for each person with disabilities. The profiling will take longer and will be used to learn more about the situation of the person with disabilities to allow a care profile to be prepared. You will also learn what the activity limitations and participation restriction are for them. This will inform your planning for protection and advocacy locally,. The identification tool, profiling tool, care profile and training notes can be found in the Annexes 11-14.

Case study

Annex 12

Identification Tool

Quick questionnaire to identify people with disabilities in the community

This quick questionnaire is for faith communities to identify people with disabilities in their communities. This is the first step to learning more about people with disabilities here and their situation, particularly whether people with disabilities are able to participate fully in family and community activities. Faith communities will then understand the key issues that people with disabilities face here and be able to support them better.

The identification visit should be quite short so you can visit many households to identify those with people with disabilities. You will then go back to those households for a follow up visit to profile the people with disabilities for a care profile. It is good for two people from the faith community to visit households together; one should be a woman. The team can ask the questions in local language to be sure that they are understood. The person with disabilities should answer the questions. If this is not possible then someone else can help.

At the start of the visit, introduce yourselves as community based volunteers; explain the purpose of the visit (why you are asking the questions), how the information will be used (to find out who are the people with disabilities here to be able to support them better) and how long the visit will take. If the person is happy to answer the questions and share information, ask them to confirm this by signing the form. If you want to take photos or use the story more widely, explain this and ask if they are happy with this.

Explain that they can stop at any time, and they don't have to answer a question if they don't want to. **Remember that the focus of the visit is people with disabilities**, so try and capture these aspects of difficulties getting or living here. If someone with disabilities is identified through the questions in **Section 1**, please continue with the questions in **Section 2**, for each person with disabilities in the household (using extra forms as needed).

Names of visitors		
Names of householders		

Date and time of visit:	Done, tick	Signed (by person answering)
Has everyone has been introduced?		
Have you explained the purpose of visit?		
Have you explained how the information will be used?		
Are they happy to share information? Get signature		
Are they happy to have photos taken and their story used? Get signature		

Section 1
1. When did you come to (name of place)?
2. Why did you decide to come to (name of country)?

3. Were any of these part of the reason for your coming here?	Flood		Drought		Famine		War	
	Other, please describe:							
4. What is your country of origin?								
5. How have you found it here in (name of the country)?								
6. In your coming to Zambia, were you accompanied by others?								
7. Briefly, is it possible to tell me how you managed to reach here? Did anyone have particular difficulties?								
8. From the story you have told me, on that journey did you manage to come with everybody?								
9. This is interesting, has life been easy for you her in (name of place)?								
10. From what you have told me, can you give me examples?								
11. Other comments								

Please complete these questions for each person with disabilities in the household

If there is more than one person with disabilities, use extra form for each person

The person with disabilities should answer the questions, if this is not possible then someone else can help.

All the questions below refer to the person with disabilities, rather than the householder.

Section 2			
Personal information of person with disabilities			
Name of person with disabilities (family, given)			
Sex	Male	Female	
Year of birth (estimate if not known)			
Country of origin (and province)			
Year of arrival in this camp			
Languages spoken			
Faith community			
Family situation			
Name of key person you live with			
Relationship to you			
Other information			
Contact information:	Block		
	Road/community/cellule		
	Plot/house		
	Cell phone		
Householders name, if not person with disabilities			
Name of person responding			
(if it is not person with disabilities)			
Relationship to person with disabilities			
Please answer the following quick questions about yourself (the person with disabilities/impairment)	No	A little (mild)	A lot (severe)
Do you have difficulty seeing?			
Do you have difficulty hearing?			
Do you have difficulty speaking, being understood?			
Do you have difficulty understanding, remembering, concentrating, learning?			
Do you have difficulty moving and reaching/using objects?			
Do you have difficulty coping with your environment?			
Is the impairment the result of:	No	Yes	Don't know
Chronic disease (long term illness)			
Injury/trauma (physical)			
Trauma (mental)			
Other (including since birth)			

Daily living	Yes, completely	Yes, with help	No
Can you take care of your daily needs?			
	Always enough	Sometimes enough	Never enough
If you need care, is the regular care enough?			

Additional questions for children	Yes, every- thing	No, not everything	No
Are you able to do all the things that other children your age can do, at home and at school?			
If not, can you or you carer explain more			

Summary of main disability (what is the main disability, how does it limit full participation in daily life)

Other comments:

Annex 13

Annex 13: Profiling tool

Questionnaire to learn about people with disabilities and their situation

This questionnaire is for faith communities to learn more about people with disabilities and their situation here. In particular, to learn whether people with disabilities are able to participate fully in family and community activities here. Faith communities will then understand the key issues that people with disabilities face and be able to support them better.

Try to arrange this profiling visit in advance, as it will take time to answer all the questions. It is good for two people from the faith community to visit the household together; one should be a woman. The team can ask the questions in local language to be sure that they are understood. The person with disabilities should answer the questions. If this is not possible then someone else can help.

At the start of the visit, introduce yourselves as community based volunteers; explain the purpose of the visit (why you are asking the questions), how the information will be used (to prepare a care profile for them, but also to learn about key issues for people with disabilities here to be able to support them better) and how long the visit will take. If the person is happy to answer the questions and share information, ask them to confirm this by signing the form. If you want to take photos or use the story more widely, explain this and ask if they are happy with this.

Explain that they can stop at any time, and they don't have to answer a question if they don't want to.

Names of visitors		
Names of householders		

Date and time of visit:	Done, tick	
Has everyone has been introduced?		
Have you explained the purpose of visit?		
Have you explained how the information will be used?		Signed (by person answering)
Are they happy to share information? Get signature		
Are they happy to have photos taken and their story used? Get signature		

Please complete these questions for each person with disabilities in the household.

The person with disabilities should answer the questions, if this is not possible then someone else can help.

In all cases the questions refer to the person with disabilities.

Personal information	
Name of person with disabilities (family, given)	
Sex	Male <input type="checkbox"/> Female <input type="checkbox"/>
Year of birth (estimate if not known)	
Country of origin (and province)	
Year of arrival in this camp	
Languages spoken	
Faith community	
Family situation	Name of key person(s) you live with
	Relationship to person with disabilities
	Other information
Contact information:	Block

Road/community/cellule	
Plot/house	
Cell phone	
Name of person responding (if it is not person with disabilities)	

Questions about your disability and the impact it has on your daily life

1. Can you take care of your daily needs?		Yes, independent	Yes, with some help	No, fully dependent
	Eating/drinking			
	Dressing			
	Washing			
	Using toilet			
2. Do you find it difficult to communicate or relate to people?		No	Yes, a little	Yes, a lot
	Understanding/following instructions			
	Speaking			
	Hearing			
	Expressing your needs, being understood			
	Seeing			
3. Do you use anything to help you with daily life?		Yes	No	Needed
	Eye glasses			
	White cane			
	Guide stick for someone to lead them			
	Walking stick			
	Crutches			
	Walking frame			
	Wheelchair or tricycle			
	Low trolley			
	Artificial arm or leg			
	Hearing aid			
	Other, please describe			
4. Do you find it difficult to move or move differently from others?		No	Yes, a little	Yes, a lot
	Sitting			
	Standing			
	Walking			
	Using hands/arms for daily activities			

5. Questions for children:		Yes, everything	No, not everything	No
	Are you able to do all the things that other children your age can do?			
	If not, can you or you carer explain more			
	Are you participating at school?			
	Are you progressing at school?			
	If not,			
	Do you play with other children?			
	Do other children play with you?			
	If not, can you or you carer explain more			
	Any other comments:			
6. Do you have any pain (over a long time)?		No	Yes, a little	Yes, a lot
	Where in your body? Please describe			
7. Do you have any deformities? for example: amputated/missing arm, foot bent the wrong way, restricted/small growth		No	Yes, a little	Yes, a lot
	If yes, please describe			
8. Do you have mental problems? for example caused by trauma or abuse		No	Yes, a little	Yes, a lot
	Recurring nightmares			
	Panic attacks			
	Depression			
	Difficulty sleeping			
	Fear of loud noises/sudden movements			
	Fear of crowds			
	Fear of open spaces			
	Fear of enclosed spaces			

	Other, pleased describe		
9. Do you have other behaviour that is difficult for you and the household?	No	Yes, a little	Yes, a lot
	If yes, please describe:		
10. Do you have:	No	Yes, a little	Yes, a lot
	No feeling or movement in your hands or feet (paralysis)?		
	Strange movement of your body (such as spasms, shaking)?		
	If yes, please describe:		
	Fits?		
	Albinism?		
	Difficulty learning?		
	Many or complex difficulties?		
	Have any other disabilities? Please, describe		

Details about your disability and treatment

11. How long have you been affected by your disability?	No	Yes	Year
	Since birth?		
	If not since birth, when did it happen? Is there a known cause? (Describe)		
	Did the condition get worse with displacement?	No	Yes, a little
	If yes, please describe		
12. Have you received any previous treatment?	Yes, enough	Yes, some	No
	Describe (where, when, by whom, results)		Year

13. If you have not had any previous treatment, why not?		Yes, enough	Yes, some	No
	Lack of knowledge about it			
	Economic problem			
	Transport problem			
	Access difficulties, for example steps/stairs, lack of help in understanding, attitudes (ignored or turned away)			
	If yes, please describe:			
	No doctor or specialist in area			
	Other, please describe			
14. What services/support are available in the camp?		Enough	Some	None
	Please describe what is available and who provides it			
15. What treatment do you get now?		Enough	Some	None
	Describe (where, when, by whom, results)			

Your involvement in family and community life

16. Do you participate in family activities/family decisions?		Yes, Fully	No, only partly	No, not at all
	Please describe how you are involved in family activities and decisions			
	If you do not participate, please describe why			

17. Do you participate in community activities? For example, community meetings, faith meetings, elections, festivals, ceremonies		Yes, Fully	No, only partly	No, not at all
Please describe how you are involved in community activities, include any role you have				
If you do not participate, please describe why				
18. Do you feel respected and treated as any other family / community member?		Yes, Fully	No, only partly	No, not at all
If not, please describe why				
19. What are you good at? What are your particular gifts, skills, knowledge, experience, role? For example: problem solving, prayer, listening, singing, history, culture, languages, fishing, sewing, basket making, mending things, peace and reconciliation, leading groups, church leader, representing people with disabilities				
Please describe what you are good at, even if you do not do it at the moment				
20. What do you do each day?		Yes, a lot/ always	Yes, a bit/ sometimes	No, never
Help at home				
Go to school				
Sit at home				
Work				
If yes, please let us about your work				
Other, please describe				

About help and encouragement you get from your family and community in daily life

21. Thinking about your daily needs, what help do you need?			
	Please describe		
22. Who usually helps you?			
	Mother or father		Husband or wife
	Brother or sister		Child or children
	Grandmother or grandfather		Grandchild or grandchild- dren
	Other relative, please explain who		
	Other person, please explain who		
23. Do you get other help and encouragement from:		Yes, a lot	Yes, a little
	Your church/faith group?		No
	The community?		
	An organisation?		
	Somewhere else?		
	If yes, please describe		
24. Have you ever heard a faith group speak out in support of people with disabilities?		Yes, a lot	Yes, a bit
	If yes, please describe		
	If not, what would you like them to say		

25. Do you ever feel isolated or vulnerable?		Yes, a lot	Yes, a little	No
	If yes, in what way?			
Could the faith communities help?		Yes, a lot	Yes, a little	No
	If yes, in what way?			
What would you do to bring about the change you want to see in your life?				
	Describe			
Any other comments				



Annex 14

Annex 14: Care profile for refugees living with disabilities

Personal information			Photo if possible	
Name (family, given)				
Sex	Male	Female		
Year of birth (estimate if not known)				
Country of origin (and province)				
Year of arrival in this camp				
Languages spoken				
Faith community	Christian	Muslim		Other
Contact information:				
Cell phone				
Camp	Block	Road/community/cell	Plot/house	
Family situation				
Name of key person you live with (family, given)				
Relationship to you				
Householders name, if not yourself or key person named above (family, given)				
Difficulties:	No	Yes, a little (mild)	Yes, a lot (severe)	
Seeing				
Hearing				
Speaking, being understood				
Understanding, remembering, concentrating, learning				
Moving and reaching/using objects				
Coping with your environment				
Is the impairment the result of:	Yes	No	Don't know	
Chronic disease (long term illness)				
Injury/trauma (physical)				
Trauma (mental)				
Other (including since birth)				
Daily living	Yes, completely, independent	Yes, with help	No, totally dependent	
Able to care for daily needs				
Need care for:				
Eating/drinking	Dressing	Washing	Using the toilet	
If care is needed,	Always enough	Sometimes enough	Never enough	
Is care received				

Summary of main disability (what is the disability, how does it limit full participation in daily life)

Notes on the history of your disabilities and any treatment

History (when it started, what happened, what treatment you had, what was the result, assistive devices)

Treatment (at the moment, including assistive devices)

Comments (including vulnerabilities and unmet treatment/rehabilitation needs)

Your participation in family and community life	Yes, fully	No, only partly	No, not at all
Family activities and decisions			
Community and faith activities			
What you are good at (abilities, skills, roles in home, faith community and local community)			

Help and encouragement you get from your family and community in daily life

Current care (help you get with daily activities)

Name of person who helps you (family, given)

Relationship to you

Address: if not living with you

Block

Road/community/cell

Cell phone

House/plot

Comment:
Other help and encouragement you get
Unmet care needs (what else you need to participate more fully in daily life)
What you want to do to bring about the change you want in your life

For Children	Yes, completely	Yes, with help	No
Able to do all the things that other children your age can do			
Able to participate at school			
Able to progress at school			
Able to play with other children			
Other children play with you			
If not completely, please describe change needed			

Annex 15

Annex 15: Example of letter advocating to a refugee agency on behalf of a refugee with disabilities

The letter below is to advocate to a refugee agency on behalf of Chantale Karana for support to be able to complete her education. Similar letters will also be sent to the head teacher at the secondary school and the refugee officer at the camp offices to get their support for Chantale to be able to complete her education.

Meheba Refugee Settlement
Meheba
Solwezi
Zambia

7th October 2014

Re: Chantale Karana, Block D, Road 36, House 48

Dear Mr Kasimba

I am writing to ask for your support for Chantale Karana to get access the high school in Meheba settlement in Block B. Chantale is a bright young lady who completed her education to grade 8 in Mwange refugee camp in 2009. Since moving to Meheba however she has not been able to get to school. She longs to complete her education and has the potential to be a teacher as she aspires.

As a child Chantale contracted polio, which has left her partially paralysed and unable to walk. The wheelchair that she used in Mwange camp has not been strong enough for the conditions in Meheba refugee settlement and is broken beyond repair.

On behalf of the disability association in Meheba refugee settlement, we are advocating for Chantale Karana to be assisted with a tricycle to allow her to reach Meheba High School to complete her education, as is her right, under the UN Convention on Rights of Persons with Disabilities.

Chantale is a young lady of great potential. By supporting her to complete her education, you would be helping her to become a productive member of the community. Her positive attitude is catching. She would make an excellent teacher if you can help her with the crucial next step to completing her education. A small investment now in a tricycle would pay back richly in the future, with a well educated sensitive leader of the community.

I trust that you will look favourably on this request.

Yours sincerely

JohnBahati

John Bahati, Secretary, Meheba refugee disability group

Annex 16

Annex 16: Examples of linking to other organisations

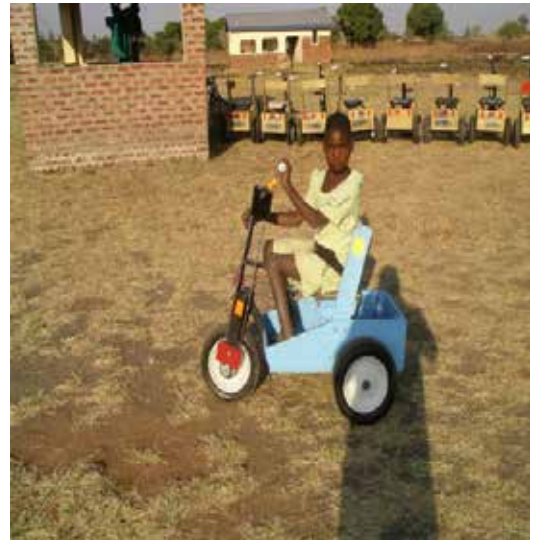
By registering as an organisation with the government, a local group working with people with disabilities can work more effectively with other organisations for the benefit of their people with disabilities.

This could be joining with them to advocate for better provision of services for people with disabilities, for example provision of better mental health support for people in the camp, or access to special schools for children who are not be able to be integrated into local schools.

Once registered, it is also possible to link with organisations that provide services to people with disabilities. For example, networking with organisations that visit to provide eye care such as cataract surgery, or that provide wheelchairs or tricycles.

Here is an example from Zambia. Through the Anglican Alliance website, the Lusaka disability project was identified and contacted. Their goal is to improve the mobility of people with disabilities and one of their activities is to provide wheelchairs made by a Methodist church project in Copperbelt, Zambia. A lovely reply came back with details of the Director of the Personal Mobility Transport project in Kitwe. They would be happy to hear from the groups in the camps in Zambia, Burundi and elsewhere that are registered to explore providing wheelchairs for those in need.

Here are some photos of the Personal Mobility Transport (PET) that they produce:





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