



Inclusion of children with a disability in the programs of Help a Child

Introduction

Help a Child is a Christian, child-focused development organization working with local partners in Asia and Africa. The Head-office is based in the Netherlands, Zwolle, where the organization is known under the name Red een Kind. Help a Child wants every child to have a loving and dignified existence and a promising future.

Every child means every child. Also children with disabilities. Worldwide children with disabilities are one of the most marginalised and excluded groups, experiencing widespread violations of their rights. They are often neglected and discriminated. The impact of discrimination against children with a disability can deny them access to education and health care, opportunities for play and family life, an adequate standard of living and the right to be heard. Beside this, children with a disability encounter a higher vulnerability to physical and sexual abuse and neglect.

Help a Child aims to be inclusive for children with disabilities in its community based programmes. Children with a disability can also be selected as sponsorships ambassadors or the Community Ambassador Model (CAM), the extra costs are covered by the sponsor model CAM Plus).

This document is meant for country offices and partner organisations to:

- A. Give information about the general concept of 'disability inclusive development'.
- B. Try to answer the most frequent asked questions of partners of HELP A CHILD about the inclusion of children with a disability in the programs and the selection of child ambassadors.

A. Disability and Inclusive Development

Disability

The UN Convention on the Rights of Persons with Disabilities¹ defines persons with disabilities as including “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. Where an impairment may have an influence on the activities that a person can do, the actual disability is a result of that impairment in an inaccessible and exclusive environment.

When we speak of persons with disabilities we refer to a very diverse group of persons that have different impairments and also experience different degrees of exclusion. People may become impaired and subsequently disabled at birth or during their life; it can be a result of a disease (for example leprosy), accident, violence or age. It is important to keep the diversity among persons with disabilities in mind.

About 1 billion (15%) of the world population has a disability, and they are often among the most marginalised of the poor. The World Report on Disability (2011) has found that 75-90% of persons with disabilities in the South live below the poverty line. Vulnerability, disability and poverty are interrelated and are elements of the same vicious cycle. Development efforts to enable people to break out of the poverty trap need to be inclusive to effectively reach out to those that find themselves among the poorest of the poor.

Working with persons with disabilities in development programmes is not the secluded domain of disability specific organisations. About 80% of persons with disabilities can participate in social life without any specific additional intervention, or with low-cost and simple community-based interventions that do not require any specific rehabilitation expertise. The other 20% of persons with disabilities may need specific interventions (for example, providing a prosthesis or a wheelchair, physiotherapy or surgery). But after referral to disability-specific organisations such as orthopaedic workshops, physiotherapy services and special-needs educational institutions, many of them would still be able (and desire!) to participate in mainstream development initiatives.

The UN Convention on the Rights of Persons with Disabilities acknowledges the protracted poverty dimension of disability, the need for a rights-based approach towards persons with disabilities, and the importance of inclusion. The Convention is signed and ratified by more than 150 countries.

Barriers for persons with disabilities

¹ <http://www.un.org/disabilities/convention/conventionfull.shtml>

People with disabilities are not always purposefully excluded from development activities. They are often not able to attend community and development activities because of barriers that prevent them from accessing activities and information. Barriers refer to any process, mind-set or structure that prevent people with disabilities from equal access to information, facilities and basic services that are available to the general population. It is because of barriers that persons with disabilities are prevented from full and effective participation in society. There are four types of barriers:

Attitudinal barriers: prejudice, discrimination and stigmatization because of the disability.

Physical barriers: physical barriers that prevent persons with disabilities from participating – these include the absence of ramps, for example.

Communication barriers: communication issues that prevent persons with disabilities from full and effective participation. Some examples include: lack or inadequate signage to guide people who are blind, deaf or have intellectual impairments, lack of information in different formats such as Braille, large fonts and sign language.

Institutional barriers: the failure to make provisions for persons with different types of disabilities in national or organizational plans, policies, legal frameworks, data collection, strategic plans etc.

Inclusive development

Inclusive development can be defined as an approach which respects the full human rights of every person, acknowledging diversity, eradicating poverty and ensuring that all people are fully included and can actively participate in development process and activities, regardless of age, gender, disability, state of health, ethnic origin or any other characteristic.

Disability inclusive development can be defined as follows: “Ensuring that all phases of the development cycle include a disability dimension and that persons with disabilities are meaningfully and effectively participating in development processes and policies”.

Inclusion is joint responsibility of all development stakeholders:

- Mainstream NGOs
- Government
- Disabled people organizations (DPO's)
- Disability specific NGOs

Each of these stakeholders has a specific role to play.

The role of mainstream NGOs is to open up projects for people with disabilities: to remove the barriers and make services and projects accessible. There is no need to become disability expert.

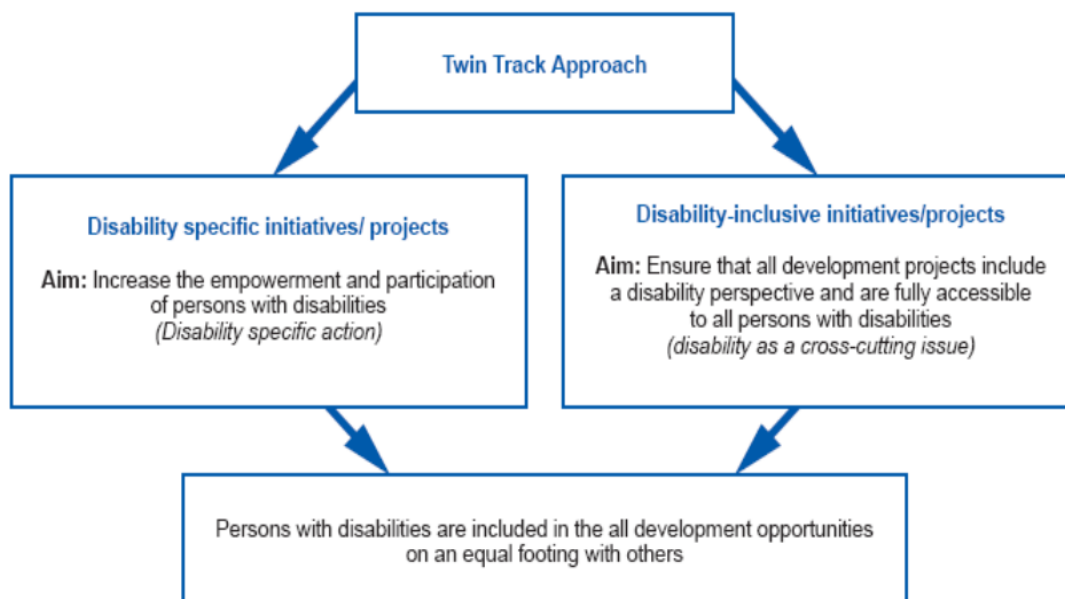
The role of government is to create a conducive environment for inclusion, bringing all legislation and policies in line with UN Convention on the Rights of Persons with Disabilities. This also means making sure that people with disabilities can access all government services, programs and schemes. This includes access to rehabilitation and health services.

The role of Disabled Peoples Organizations (DPOs) is to advocate for their rights and to influence policy makers, to empower and strengthen the voice their of members and to offer first hand expertise on disability and inclusion.

Disability specific NGOs can play an important role in strengthening DPOs and support empowerment. But they can also develop models of inclusion/ do research and facilitate learning and sharing between all actors. Last but not least they can play a role in (supporting government in) providing disability specific services.

Twin track approach

Disability inclusion can be achieved by combining two approaches – disability mainstreaming and disability-specific interventions. This is called the twin-track approach. These approaches need to be addressed at the same time. This can be visualized as two rail tracks running parallel to each other: both needed to arrive at the final destination. The activities under the specific track should steer, as far as possible, towards inclusion in society. The adagio is: inclusion where possible, specific when needed.



The costs of including people with disabilities is often used as an argument against adapting development programmes, but the reality is that including people with disabilities in mainstream development is more effective and efficient than excluding them, and costs to make that happen range from 3-7% of the total budget of a development programme.

Disability inclusive development honours the following principles:

- Attitude: respect and dignity
- Communication: inclusive communication
- Accessibility: barrier-free environment
- Participation: active involvement

Two Levels: Programme and Organisation

To effectively mainstream disability in development work, it is important that it takes place at both programme and organisational level:

Programme level: At every stage of the project cycle disability inclusion need to be considered, and also per thematic sector specific points of attention are required.

Organizational level: This is to ensure that inclusion is not isolated to programmes only, inclusion actually becomes part of the culture of an organisation.

B . Frequent asked questions from partners of HELP A CHILD on disability inclusion programming and selection of children for ambassadorship

1. Program content

What is Help a Child aiming for with the trajectory on disability inclusive development?

Help a Child wants to assure equitable access to and benefit from health, education, local government services, and participation in the community for all children with disabilities in its programs.

What are our approaches to reach this goal?

Approaches to working with children with disabilities include:

- Raising awareness about their rights
- Promoting a positive attitude of the parents and the communities towards them
- Facilitating their inclusion and participation in ongoing development processes by removing barriers
- Linking them to service providers

What types of impairments can we distinguish?

Types of Impairments:

- Physical impairments
- Hearing impairments
- Vision impairments
- Speech impairments
- Psycho social impairments
- Intellectual impairments
- Learning impairments

Are we focussing on only children with disabilities or also youth and adults?

The selected CAM children represent the group of children and people living with disabilities. So for example, if there are parent-, youth- of farmer groups, try to make them

inclusive as well. But, being a child-centred organisation, HELP A CHILD will focus in the first place on the wellbeing of children. All activities should contribute to that goal.

Are we including children with all kind of impairments or do we focus on a specific impairment, for example blind children?

We don't focus on children with one specific type of impairment. The idea is to include **all** children with disabilities as much as possible in our community based programs, not making exceptions for one type or another. However it is possible that certain disabilities cannot immediately be supported through services because lack of the availability of these services.

Can we use the twin track approach?

Disability inclusion can be best achieved by combining two approaches – disability mainstreaming and disability-specific interventions. This is called the twin-track approach. These approaches need to be addressed at the same time. The adagio is: inclusion where possible, specific when needed. Help a Child is fully involved in the disability mainstreaming. However for the disability-specific interventions referral happens to specialized organizations and/or service providers as much as possible.

How to manage the expectations from parents and the community?

There are often high expectations towards the program from the parents and the community when it comes to children with a disability. This is understandable and the expectations should be well managed. Be clear and honest about the content of the program. Inform the parents and the community at forehand exactly how the program will look like in order not to create false expectations. Explain what you do, **and what you don't**, and involve them in the decision making. It is also important to show the good results, although it might take some time to deliver them.

What to do in case if the child need any devices? What if further diagnosis is needed or surgery? How will this be paid?

HELP A CHILD does not promote directly giving medical services or devices. Programs will refer as much as possible to other organizations (regional or global level) that provide such services. Be assured of a good mapping of different service providers (NGO's, government) in order to be aware of the different stakeholders and their services in the area.

The possibilities to cover costs might differ per country. Be assured you have the right knowledge about the different regulations, schemes and funds for people with disabilities from the government that apply in your situation.

To cover any costs, it can be considered that through SHG's or in collaboration with the CLA, the community could create funds to support in the costs for the children that need further devices, diagnosis, treatment or surgery.

The program can promote registration of children and persons living with disabilities to enhance their access to health services.

The program can also promote enrollment to and lobby and advocate for increased access to Health Insurance Funds and to empower right holders to claim their rights from duty bearers.

However, under certain conditions costs for devices can be included in the annual budget of the partner and thus supported by HELP A CHILD.

Criteria:

1. Possibilities to cover these costs have been exhaustively investigated: either through other service providers, either through government schemes, either through savings by SHG's (social fund), or any other available fund. When covering of costs is possible by one of these options, requests for costs for devices will not be considered by Help a Child.
2. Parents of the child need to be an active participant for the program.
3. An explanation is given how to make the provision of devices sustainable on the long term.

And, under specific conditions funding can be made available from 'The Emergency Fund' of HELP A CHILD. This fund is meant to cover any medical surgery or treatment for children (0-18) of which the costs are beyond the family and community capacity. Funds will only be made available if the request is in line with the set criteria. Each CPD has an one-off 4.000 euro available to use at his or her discretion. This is an one-off fund and not yearly recurring fund.

Criteria are:

1. Possibilities to cover these costs have been exhaustively investigated: either through savings by SHG's (social fund), either through Health Insurance Systems, either through covering by any other Fund made been available by the government. When covering of costs is possible by one of these options, requests for 'The Emergency Fund' of HELP A CHILD will not be considered.
2. Parents of the child need to be an active participant for the program.
3. Involved stakeholders are expected to contribute to the costs as well.

What if the mapping indicates that in practice there is absence of service providers that can assist with needed devices?

We can understand your fear that awareness creates a demand that is not able to be met by government, other service providers or the program. Before starting with the program be assured of a thorough assessment of mapping of the available service providers (are they really not there?). And if not, determine to what extent lobby can happen to persuade services to come to the area to provide the necessary services. Is it possible for services to be provided from the neighboring district or province?

In case there are really no service providers at all, and also lobby on the short term is expected to give no results, this is a no-go for the program (see criteria go-no under section program management)

Can we make an exception to contribute in the extra costs for parents (for example for transport to schools?)

No, all principles for our community based programs (no hand-outs, no contribution in costs etc) will also go for this target group. Funds might be created through the SHG approach.

Can we include children with disabilities in existing children groups?

Yes, including them in existing children groups can be a great way of inclusion.

Specifically:

- Child Rights Clubs: specific emphasis to include all children including children with disability in school rights clubs.
- Community Children's Groups: Give attention to children with disability and their involvement in regular play and learning activities during community children's group sessions.

Do we need to support inclusive education any time or are there cases of children who need to go to a special school?

The adagio is: inclusion where possible, specific when needed. In a lot of cases children with disabilities are able to go to a regular school through improvement in the access of the building, having the necessary devices, changes in attitude of the community, training of the teachers etc. However, there might be some cases where special education is better in the interest of the child. There is no clear guideline to make this distinction and shall be considered per situation and per child. Often a 'mixed solution' is also possible: for example to train special needs teachers to be paid as volunteers for a specific period of time to learn teachers how to integrate inclusive education in mainstream schools.

2. Program management

Can we introduce disability inclusion half way the program, even if our program will only run for a few years more?

Ideally, inclusion of disability will directly start from the beginning of a program. But, in practice, most programs are several years on the way. To allow sufficient impact on the lives of the children programs still need to last at least 3-4 years. We do realize this might give you some challenges, that is why we offer you the support of an expertise organization or consultant to guide you in this process.

Is there a go-no go moment in the process and what are the criteria?

Disability inclusion in itself can be started at any time and any place. Within any program steps can be made, even when the steps are small. However, there are some criteria that **need** to be met to be able to implement a program of disability inclusion in **combination with the CAMPlus model funded by HELP A CHILD:**

1. An in-depth context analysis of the prevalence and types of disabilities, perceptions of the community, including mapping of services, DPO's and service providers and government policy need to be carried out.
2. From the context analysis it became clear that there are service providers available in the area for children with disabilities.
3. There is an opportunity to get financial resources to get access to services.
3. The partner makes a plan which describes the process of financial sustainability of the program.
4. The program will at least take 3-4 years before it has come to an end.
5. The capacity of the organization needs to be sufficient.
6. The partner is willing to implement the CAM Plus program according the principles of inclusion and sustainability.

When one of this criteria cannot be met, this should be considered as a no-go.

Will also activities on organizational level (besides program level) be funded by Help a Child?

During the organizational assessment several gaps might occur on the organizational level. Activities to improve on this, can be included in the annual plan of the partner.

How much budget will be allocated per program?

Research has shown that between 3-7% of the existing budget is extra needed to make the program inclusive. The choice for the activities (and thus the budget) might differ per context and is always based on the context analysis and the advice of the expertise organization. By linking CAM Plus sponsors to the program additional funding is provided specifically for the support of the inclusion of disabled children.

What capacity (time, knowledge and skills) are needed in the country offices and partner organizations to organize this?

It is very important that disability inclusion becomes a shared responsibility of everyone in the team. A disability inclusion training for everyone is needed. Beside this, it is advisable to make one team member a 'focal person', one who has the mandate to guide the overall disability inclusion processes within the organization. This doesn't need to be a fulltime position, but make sure some time is allocated for this task. With regards to time needed: disability inclusion is especially a matter of mind-set change whereby staff of a program continuously consider the needs of children with a disability. Make the community owner of the inclusion of persons with disabilities. Time will be especially devoted towards awareness and capacity building of SHG's / CLA's and or community volunteers who link up children with a disability with services providers and /or DPO's.

How can we make the introduction of this trajectory manageable?

Start small and gradually expand the area of interventions and the number of disabled children you focus on. Select the ambassadors from a limited number of villages and limited geographical area and gradually expand as you increase your knowledge and experience. First focus on the linking of persons with disabilities with service providers of ambassadors and then the children in the immediate vicinity of these ambassadors and then expand the geographical area.

Child ambassador model

What is our promise to our sponsors?

We promise that at the end of the program:

- Children with disabilities are actively involved in daily activities of children (including decision making processes in for example children groups) and can express their opinion freely.
- Children with disabilities can move around freely, independently, with confidence and respect and have access to health and educational services.

What is the role of CAM ambassadors with a disability?

The role is not very different than other CAM ambassadors: they represent a bigger group of children in the community sharing their experience with sponsors about the improvement of their wellbeing through a community based program. So, the CAM ambassadors with a disability represent the group of children and people in the community with a disability.

Will only the child that is selected as ambassador profit from the program, or other children with disabilities as well?

Child ambassadors living with disability are representatives of **all** children and people living with a disability in the program area. The ambassadors should not receive more or less than other children. All children in the selected target area living with disabilities should ideally be part of the inclusion interventions.

What are the selection criteria for ambassadors?

The criteria for selection of potential child ambassadors living with disability are:

- Child for whom we expect that the program can make a significant difference in their lives. As sponsors expect their investments to make a difference in the life of the child with a disability
- Child from a household whose parent is a member of a Self Help group and is willing to participate in all activities organized for the wellbeing of the child.
- Child and parents are willing to participate in program activities (incl. go to school when possible)

- Child from poor families
- Child living and staying within the program area
- Child aged between 6 and 15 years (exception can be made, but only after consulting HELPA CHILDA)
- Child is willing and able to share his or her input in a communication to a sponsor possibly with the support of others (child does not need to do the writing him/herself).

What to do if the selected child ambassador is not able to write or draw without support of others or alternative means of communication?

In case a child is not able to communicate without support of others, think about alternative means of communication. For example, if a child is deaf and the child nor his or her environment know sign language well, it is important to work on sign language skills. This will also support the child when going to school and interact with family members, and the community as a whole. This can be done by identifying resource persons in the locality, for example a person who is hard of hearing who knows sign language. If a child has an intellectual impairment, the child might communicate about his or her life through drawings.

In case of a FAM program can we select children as ambassadors?

Yes, in case of a FAM (Family Ambassador Model) program children with a disability can be selected as the ambassadors.

When should the selection of ambassadors take place?

The selection of ambassadors should ideally take place like any other selection of ambassadors. First the self-help groups are formed, after this the selection will take place. If this is not possible, because the SHG's are already formed try first to select children with a disability among the SHG members who already know how to benefit from the program. Be very clear from the start what the children and parents can expect from the program.

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