Volunteers' Orientation Guide

How to Care for Children with Disabilities

YEKOKEB BERHAN/Pact PROGRAM FOR HIGHLY VULNERABLE CHILDREN

JANUARY 2014

Table of Contents

ACKNOWLEDGEMENTS

This volunteer's orientation guide on "How to Care for Children with Disabilities" was made possible by the generous support of the American people through the United States Agency for International Development (USAID), Cooperative Agreement Number AID - 663 - A - 11 - 00005. The contents are the responsibility of ChildFund and its Yekokeb Berhan Program for Highly Vulnerable Children (HVC), and do not necessarily reflect the views of USAID or the United States Government.

Yekokeb Berhan is indebted to the Hesperian Foundation for their resources that were used to develop this orientation guide. They produce wonderful materials and have been very helpful in our correspondence with them. Two the pictures in the annex and much of the information included in this document were taken from different books and other documents they published, with their permission. Our appreciation also goes to all organizations and individuals in Ethiopia who provided input during the preparation of this Volunteers' Orientation Guide. We would also like to extend our deep appreciation to our colleagues at ChildFund, who led the effort to develop this Guide, as well as to our colleagues at Pact and FHI360 for their assistance and support. Everything we do at Yekokeb Berhan is a team effort, and this volunteer's orientation guide is no exception.

January, 2014

Pact
Bole Kifle Ketema, Kebele 20 House No. 2129, P.O.Box 13180,
Addis Ababa, Ethiopia
Telephone: (251) 11-661-4800, (251) 11-662-3796
Fax: (251) 11-662-3789 e-mail: pact@ethionet.et

1. INTRODUCTION

1.1. Background

In most parts of the world, someone with a disability is defined by that disability: he or she is simply known by the limp, blindness, or whatever other impairment the person has. Moreover, the personal challenges that person faces often go well beyond the disability itself, as the individual is excluded from education, work opportunities, and inclusion in society. Much of this relates to poverty and also makes poverty worse. The lack of basic health and rehabilitation services in poor communities can make disabilities more common and more severe.

The most important thing to know about disability is to never make assumptions: Someone with a disability can be physically very fit and strong and/or highly intelligent.

The most important thing to change about disability is attitude – yours and mine: Focus on what the person CAN do (not on the impairment or problem), and you may be amazed!

The most important thing to do is to seek diagnosis (testing) and treatment immediately - many forms of disability can be prevented or improved in this way.

Often, disabilities can be prevented by early testing and treatment – for example, if the person has an illness or is infected by HIV and AIDS. Early diagnosis (testing) and treatment is essential. Also secondary disabilities develop can be prevented with early care – meaning a condition that makes things worse for a child that already has one disability.

The main challenge is that many parents and primary caregivers of children with disabilities do not understand why their child is different than other children; they may just pray that things will improve and not seek any assistance. This can make the situation worse. As they grow older, children with disabilities – and their caregivers -- face unexpected challenges that may overwhelm them. These may include stigma, isolation, anger, additional illnesses or disabilities, and fear of the future.

But these parents and primary caregivers are not alone. Many conditions can be successfully treated, if diagnosed early. Moreover, affected families with children can support each other with advice and referrals. Through programs like Yekokeb Berhan, there are neighbors and volunteers who can also help. Getting a child tested – diagnosed – at a health clinic or hospital is an important first-step. After that, many governmental and non-governmental organizations exist that can be called on for additional support.

Caregivers can learn to cope with the demands of parenting a child with disability once they learn more about the issues with which they are dealing, and how to address them. If they can relax and take the positive steps, their child will benefit, and this will make things easier for the entire family. A key factor is to focus on what the child or adult with a disability CAN do, rather than on what she or he can't. Hence, we like to think of persons with disabilities as DIFFERENTLY ABLED, rather than DISABLED. This attitude change can go a long way. Throughout this document we will also try to create the awareness on how to identify a very young child with a disability (as early diagnosis is very important), and focus on what can be done to help a child with a disability - prepare for a fulfilling and independent life in the future.

1.2. Objective of the Orientation Guide

According to the assessment made by Yekokeb Berhan Program for Highly Vulnerable Children in 2012, children with disabilities are found as the most excluded groups in all communities across the study areas. Who are these children? Children with disabilities include, but are not limited to, those with Autism Spectrum disorders, developmental delays, learning disabilities, speech and feeding issues, blind/visually impaired, deaf/hard of hearing, physical disabilities, and mental health issues.

But often, the main barriers to inclusion and participation for these children are not the disability itself, but rather the limited capacity of families, communities and service providers to fulfill the child's needs, and the lack of access to infrastructure and services that child needs to attend school, join with others in play, and ultimately prepare for an independent life.

Consequently, this orientation document was prepared to fulfill the following main objectives:

1. Help parents, caregivers and volunteers understand that there are many different kinds of disability, and each one has different degrees of severity. We focus on the early identification of the disability, as this can often help with treatment, rehabilitation, the prevention of secondary effects, and the overall inclusion of the child in society.
2. Remind everyone that many disabling conditions can be prevented through early diagnosis (testing) and treatment. Therefore, children who are sick for more than a few days should be referred to a health clinic or hospital for diagnosis (testing) and possible treatment, This is also true when a disability is first observed or if there is a chance that the child may be infected with HIV and AIDS.
3. Help change attitudes around children with disabilities, to focus on what they CAN do, rather than on what they can't.
4. Enable volunteers and families understand what the specific abilities and disability of a child or family member, and thus to help remove the barriers that bar children with disabilities from actively participating in their own and their community's lives;
5. Get information on how to link and connect disability-affected families with important resources;
6. Build the capacity of volunteers to create an appropriate local care system that emphasizes ABILITY and INCLUSION, whereby children with disabilities can lead learn to lead self-fulfilling and independent lives.

1.3 For Whom This Orientation Guide Directed?

As part of Yekokeb Berhan's efforts to promote the inclusion of children with disabilities in both family and community life, two guides were prepared to train and orient Implementing Partner staff, government officials, volunteers and family members.

1. The first of these is a detailed manual for staff in order to develop in-house, locally based expertise. It includes a self-assessment questionnaire on Inclusion issues. This manual comes with a lot of reference material that anyone can access, and which should be easily available to staff, volunteers, and community members.
2. Given both the complexity and importance of this issue, this additional orientation manual was additionally developed for all volunteers, in order to introduce them to the information they need to provide in identification and support to family members and to the children themselves. Note that volunteers and families who care for a specific kind of disability should receive additional mentoring support using the reference manual as demand arises.

1.4 How to Use The Orientation Guide

Yekokeb Berhan community facilitators can provide the orientation to volunteers and also can use the information during community sensitization programs. It will take less than 7 hours in total to orient volunteers with this guide. The orientation has to be provided to volunteers session by session during their regular weekly meetings. There are four sessions in total, lasting from 1.40 to 2.5 hours. Thus, the training can be completed at the volunteer level over a one-month period – one session per week, the same as "Volunteer Basic Training" or "Better Parenting."

To train facilitators, the sessions can be offered in just one day – each one sequentially. (Because this includes a lot of information that is difficult to absorb, however, this method is NOT appropriate for volunteers.)

Facilitators should also encourage volunteers and caregivers to acquire further skills in supporting families and children with disabilities. They can do this through the resource manual that Yekokeb Berhan is providing. If they are interested to register for additional mentoring sessions, please contact the Inclusion Specialist at ChildFund for more information.

An information sheet has prepared by excerpting key points from the orientation guide, and it is annexed at the end. Each volunteer group should be provided with at least one copy of the information sheets to which they can refer every week. A designated volunteer from within the group should bring these to the weekly meetings – even those when “disability” is not part of the training agenda. (The issue may still come up when volunteers discuss the children they serve.) Note that these information sheets can also be used by other volunteers when conducting home visits to a family where there is a child with disability.

1.5 Methods Used

This volunteers’ orientation guide uses different participatory methods. These include pictorial explanations, group work activities, games, role plays, experiential learning and presentations. Hence, flip charts, markers, colored paper, pens and pencils will be required to provide the training. There are also several pictures in the Annex and a set of handouts, which should be reproduced for the training and for reference afterwards.

1.6 The Language Used In This Document

Most books about children with disabilities talk about the children as if they are all boys and use the word “he” to refer to any child. This happens because society holds boys to be more important than girls and that belief is built into our language. In fact, girls are not only left out of our language, they often receive less attention and care including getting less food and health care — both of which contribute to disability. In this document, we try to give equal attention to all children by using both words in a more equal way. Either “he” or “she” is used to refer to a child of either gender throughout the manual.

1.7 Structure of This Training Guide

This guide contains four distinct sessions.

1. The first session takes 2.30 hours and provides an introduction to disability and highlights the key barriers that children with disabilities often face. Various ideas and solutions will be offered that promote inclusion.

2. Session Two and Three last for 3.55 hours in total (Session Two is 1.40 hours and Session Three is 2.15 hours.) These two sessions provide an overview on different kinds of disability. Basic information is provided about children who are blind or visually impaired: children who are deaf or hearing impaired; children with learning or cognitive disability; epilepsy; and children with mobility (physical) disabilities such as cerebral palsy and clubfoot cases. There are handouts that should be reproduced for the volunteers – if not for each one, then several per

group (where the person who is designated to keep the hand-outs brings them regularly to volunteer meetings, so others can refer if needed.)

3. The final session, Session Four contains two short activities related to establishing community care system, and will take 1:40 hours.

Staff is reminded that initially, the sessions may be rolled out to staff in a one-day orientation. But for volunteers, the sessions should be held sequentially, one per week, over the course of one month.

The same structure should be used when training Community Committees, Community Care Coalitions and other interested community groups.

SESSION ONE: UNDERSTANDING DISABILITY AND THE IMPORTANCE OF A POSITIVE, CAN-DO ATTITUDE

Objective of the session:

By the end of this session participants will understand

- How to think of disability as “differently abled.”
- Appropriate terminologies to use in expressing issues related to disability;
- Explain why children with disabilities are (sometimes) excluded from opportunities and activities in which other children participate
- Identify important measures to be taken that can enhance all children’s participation and development, regardless of disability;
- What Inclusion means.

Time required: 2.30 hours in total.

Materials required: flip chart and markers, and color cards.

Introduction to the Session

Disability affects everyone. Maybe you know someone with a disability, possibly in your own family. Also, people who are not living with a disability now may have one in the future. Sometimes, the term that is used to describe people who do not have a disability is that they are “temporarily abled.” When we are very young or very old, all of us need help from others. If you become ill and need assistance, or if you become disabled in your lifetime, how do you want people to treat and describe you?

All of us need assistance when we try to do different things. If you want to travel 80 km per hour, you need an assistive device called a vehice, the same as someone with a disability would need it. Needing an assistive device does not make you less human, just as having a disability does not make the person with a disability less human, either.

Activity 1.1: What Is Disability and How Do We Refer Persons with Disabilities?

(50 minutes, total)

Discussion 1: Exploring What We Already Know
20 minutes

1. Ask everyone to think of someone with a disability, perhaps someone she or he knows. In each person's mind, answer three questions: A) what kind of disability does the person have? B) How would that person's life be different without the disability? C) How much better could that person's life be, if other people provided lots of extra support and assistance from the first time the disability appeared – for example, lots of encouragement, special education or physical therapy, helpful assistive devices, and so on?
2. Pair everyone up with one other person in the room and ask each person to share her or his thoughts with each other...
3. Briefly discuss,
   - Based on the information you shared, what different kinds of disabilities did you think of? (briefly list these, e.g. visual, deafness, intellectual disabilities, multiple/unknown, etc)
   - Was there a big difference between how the person's life is now and how the person's life could be, if that person received extra support and assistance?

     What kinds of extra support and assistance did you think of, that could be most useful?

Discussion 2: Identifying Traditional Ideas about Disability
20 minutes

1. Ask a few participants to answer, why is it important to use appropriate language and words when describing people with disabilities?

2. Pair up participants and list on a paper as many outdated and inappropriate terminologies that are sometimes still used to describe persons with disabilities in their communities. Then ask them to list as many respectful or appropriate terms that can be used to describe people with disabilities. Tell them that this is a contest: the pair that gets the most number of words in each category wins. *Note to the facilitator: if participants are not clear what you mean, take some phrases from the list on the next page and share them as an example.*

3. Ask the group that has the longest list of outdated or inappropriate terms to read their list aloud. Others may add additional terms. Then ask the group that has the longest list of respectful or appropriate terms to list theirs and write

these on a flip chart. Others should also be invited to add to these terms. Refer to the list below for any that are still missing.

Presentation: Words Used to Describe Different Kinds of Disabilities
10 minutes

The use of language and words in describing people with disabilities has changed over time. It's important that people are aware of the meaning behind the words they use when talking to, referring to, or working with the Disability Community. Disrespectful language can make people feel excluded and can be a barrier to full participation. So it is important to learn and use respectful languages continuously as language and culture evolve from time to time. We encourage you to learn and teach others on how to use respectful communication whether or not a person with disability is around.

We can agree in our sessions that every time someone uses outdated the rest of us will shout BOO or make a loud noise but every time someone uses respectful language, we will give a thumbs-up or clap, to show we approve! (*Ask everyone to agree to these rules and then practice them throughout the orientation.)*

Now, I am going to randomly saw aloud some terms that are outdated and some that are respectful and I want you to either boo or shout, or else put up thumbs up and clap, depending if you think I am saying something that is outdated or something that is respectful. Let *the group practice by booing or making noise, or else clapping or putting thumbs-up.*

Table of terms related to disability – for reference by the Facilitator

Disability	**Outdated Language**	**Respectful language**
Blind or Visual Impairment	Dumb or invalid	Blind/visually impaired, person who is blind/visually impaired
Deaf/hearing impairment	Invalid, Deaf-and-Dumb, Deaf-Mute	Deaf or hard of hearing, person who is deaf or hard of hearing
Speech/Communication Disability	Dumb "one who talks bad"	Person with a speech / communication disability
Learning disability or Cognitive Disability	Retarded, Slow, Brain-Damaged, "Special education"	Learning disability, Cognitive disability, Person with a learning or cognitive disability

Mental health disability	Hyper-sensitive, Psycho, Crazy, Insane, Wacko, Nuts	Person with a psychiatric disability, Person with a mental health disability
Mobility/physical disability	Handicapped, Physically Challenged, "Special," Deformed, Cripple, Gimp, Spastic, Spaz, Wheelchair-bound, Lame	Wheelchair user, Physically disabled, Person with a mobility or physical disability
Emotional disability	Emotionally disturbed	Emotionally disabled, Person with an emotional disability
Short Stature, Little Person	Dwarf, Midget	someone of short stature, Little Person

Activity 1.2 Barriers Faced by Children with Disabilities and Understanding Inclusion

(1.20 hour).

Discussion 1: Identifying barriers or challenges that children with disabilities face (20 minutes)

Ask participants to think of children they know who face exclusion in some way or another, due to a disability. What barriers exist in their community that might prevent a child from participating in the activities of other children her own age such as making friends; from going to school; receiving specialized services she needs etc.?

Note to the facilitator: *List the participants' responses on a flip chart, in two columns – the first column should comprise those challenges or barriers that cost a lot of money to deal with, and those that do not cost a lot of money.*

Barriers to remove that are important but require referrals or may require extra funds	**Barriers to remove that don't cost a lot of money, that we can do in our own community**
…	…
…	…

Note that this second column might include things like: Reaching out to help the caregiver, Giving emotional support and encouragement; Thinking positively about what the child CAN do; removing steps to a house; Making crutches out of local materials, etc. Refer to the box below for ideas that the participants may not think of.

Then go back to the different barriers you listed and describe which ones are physical barriers, resource barriers, attitudinal barriers and communication barriers. Refer to the description below, if you are not clear.

Reference for the Facilitator:

Barriers that children may face in being fully included in community life

- **Physical barriers** may include obstacles that affect walking or physically managing things, such as the distance a child needs to walk if he has a disability or has low energy, is malnourished, and is very young.
- **Resource barriers** related to special schools and assistive devices, such as hearing aids or a wheelchair that a child may need, which may or may not be available in the community. (*Note that schools with special education classes are more often available these days – so-called Inclusion programs – but some children may still need a special school, such as those who have intellectual disability; who are blind or deaf.*)
- **Attitudinal barriers** refer to the attitudes of others, for example, in seeing value to the person's participation. Negative attitudes can affect a child psychologically and cause the child to withdraw, become depressed, or not even try to use the abilities that he has...
- **Communication barriers** are barriers that get in the way of children's equal ability to communicate easily with the people at their homes, community and school. The reason may be due to language differences, disability or strong cultural differences.

Role Plays and Discussion (1 Hour).

1. Divide participants into three groups and give each group the copy of one scenario. Allocate 10 minutes for preparing the role plays.

2. Perform the role play accordingly, each participant should have a role (give 7 minutes for each group to perform);
3. Initiate a discussion after the role plays, following the questions listed below.
4. Capture the points raised during the discussion and highlight the most important ideas. Be sure to build on the positive ones.

Scenarios for the Role Play

Scenario 1

There is one child with a physical disability who uses a wheelchair in the neighborhood school. Riding a wheel-chair to and from school becomes a challenging experience for the girl and her mother. Moreover, her class is on the second floor and the toilet in the school is inaccessible, forcing her to leave early from school to use toilet at home . As a result, she drops out of school and she feels desperate about the situation. Imagine that you and other volunteers want to discuss the child's problem with the school administration and Parent-Teachers' Association to make changes to benefit the child.

In your group:
1) Assign the different roles for the role play
2) List the points that the school representatives are going to give you
3) Prepare a practical solution to the problems that can be taken by the family, volunteers and the school in the neighborhood and help the child to attend school
4) invite participants from other groups to reflect on the role play.

Scenario 2

In your neighbourhood there is a family with an intellectual disability (i.e., who is slow learner). The family does not want to send this child to school, explaining that this is would be a waste of time and money. The child is not allowed to play with other children, but just stay at home all day. Imagine that you and other volunteers are going to approach the family members to convince them to let their child socialize and attend school.

In your group:
1) Assign the different roles for the role play

2) List the reasons that you think the family is going to give you
3) Prepare a solution to the problems mentioned by the family and a winning argument to help the child to play with other children and attend school
4) invite participants from other groups to reflect on the role play.

Scenario 3

In the school that your child attends, the director of school refuses to admit your neighbour's child who is very hard of hearing. The director says that the child should go to a special school, but they aren't equipped to handle this child's special needs. But the specialized School for the Deaf in the city nearby says that this child can be mainstreamed, meaning that this child CAN be taught in his local school. Meanwhile, some other parents from the school complain that they don't want their children to be mixed up with the children with disabilities. They say that teaching him will take the teacher's attention away from their own children and slow them down. Some teachers fully agree with the Director's decision, some are not sure, and some say that they should try to teach the youngster. Imagine that you and the mother of the hard-of-hearing child are going to approach the director to convince him to change his mind.

In your group:

1) Assign the different roles for the role play
2) List the reasons that you think the director and the families are going to give you
3) Prepare a winning argument to help the child to attend school and change the attitude of the parents towards children with disabilities.
4) invite participants from other groups to reflect on the role play.

Discussion

- Open a discussion on the benefits they see to having all children participate together in services and community activities - what we call "inclusion." (See notes below.) What are some of the common obstacles to inclusion that must be confronted? What are some of the best strategies to use to promote inclusion?

- Ask participants to explain which role play they thought was the best, and why. (If you want, they can vote on the best role play and the winning group gets a round of applause.)

- Conclude the discussion by summarizing what inclusion means, using the main points from the discussion and from the Facilitator's Notes in the box, below.

The main points from the summary should be written on a flip chart that can be hung on the wall during future training sessions.

Note to the Facilitator: Read this aloud.

What is Inclusion?

Inclusion is the effort to include everyone in family and community activities, irrespective of age, disability, gender, HIV status, religion, ethnic and language background. Promoting inclusion means taking actions that seek to overcome the barriers that some individuals experience in trying to participate fully in services or activities, in the same way as others. The barriers may be physical (as with the steps in the first case scenario), they may be economic (not having the resources to make inclusion possible) or they may be psychological (meaning, fears or a negative attitude on the part of the individual who is excluded and/or by others in the community). Usually the psychological or attitudinal barriers are the biggest and most important to overcome, so it is best to start there.

Inclusion is both a life-long process and a never-ending goal. Removing barriers benefits everyone by fostering full participation, teaching acceptance, and valuing the diversity that exists in every family and every community.

Thus, inclusion is about (summary):

- *Welcoming and appreciating diversity*
- *Providing equal access to services for all*
- *Reaching out and benefiting all often excluded groups and individuals*
- *Reaching out and benefiting children who feel excluded.*

Activity 1.3: The Importance of early diagnosis (testing) and treatment
(10 minutes)

Often, disability can be prevented by early testing and treatment – for example, if a child has a serious illness or one that that goes on for several days. This is because some illnesses can lead to long-term impairment or death if not properly treated – for example, malaria, tuberculosis or meningitis. This is also true if a mother or child is infected by HIV and AIDS. Early diagnosis (testing) and treatment are essential and should be done in a local clinic or hospital.

Treatment is available (at no cost) for many conditions, including HIV and AIDS -- if diagnosed early. (This is discussed more fully in Session 3.) Also secondary disabilities develop can be prevented with early diagnosis and care – meaning a condition that would make things worse for a child that already has one disability.

Note to the facilitator: Read each sentence aloud and then ask all participants to repeat this after you:

The most important thing to know about disability is to never make assumptions: Someone with a disability can be physically very fit and strong and/or highly intelligent.

The most important thing to change about disability is attitude – yours and mine: Focus on what the person CAN do (not on the impairment or problem), and you may be amazed!

The most important thing to do is to seek diagnosis (testing) and treatment immediately - many forms of disability can be prevented or improved in this way.

Activity 1.4: Review - Magic Ball
(10 minutes)

Ask participants to reflect on the main points covered in this session. Ask them to think about an idea or something new that they learned that they would like to share with other participants

Toss a crumpled paper ball to a participant and ask them to share one idea and then toss the ball to someone else until all the participants cover all the main themes. Fill in gaps as necessary.

END OF SESSION ONE

SESSIONS TWO AND THREE: UNDERSTANDING DIFFERENT KINDS OF DISABILITY

Objectives of the sessions:

By the end of this session, participants will be able to:

- Understand how to recognize the basic types of disability that are most common in Ethiopia;
- Understand key actions that should be taken to ensure that children with disabilities are engaged in activities that are important for their own development and for the community in which they live;
- Get information on how to develop the skills needed – by the parent, caregiver and other community members – that will help children with each major type of disability.
- Get information on how to refer a child for early intervention and additional supports, where needed.

Materials Required: flip chart and markers, pencil and color papers and pictures (copied from the manual).

Time required: 3:55 hours. Session Two should last one hour and 40 minutes. Session Three should last two hours and fifteen minutes. (Note that Session three can be further broken down into two sessions – Activity 3.1 and Activities 3.2–3.4 – if necessary.)

SESSION TWO

Time: One hour and 40 minutes

Activity 2.1: Understanding a Child Who Is Blind or Visually Impaired

(45 minutes)

Discussion: How to identify a child with a visual impairment
15 minutes

By the end of this activity participants will be able to:

- Detect blindness or severe visual impairment in a young child
- Understand important considerations to be taken in hhelping a child who is blind or visually impaired to become independent and part of her own community.

Note to the Facilitator:

1. Start by introducing the objectives of the activity. Explain the difference between blindness (not being able to see at all) and visual impairment (being able to see only partially, or in the case of severe visual impairment, only a very little bit).

2. Ask participants how they might detect blindness or vvisual impairment in a very young child (give them 3-4 minutes).

3. Explain that it is common in many communities for families to deny that their child may have some kind of disability, for fear of rejection by the community, or because they lack hope for the child's future. Family members may also not know what to do about the matter. But if a disability is detected early, the child may be able to get medical treatment to improve the situation (sometimes this helps, but not always), and the family can be taught to provide support that will build on the child's strengths – on what the child CAN do – and also obtain additional assistance from other organizations or special schools, if needed. This approach is important for all disabilities, not just those involving sight.

4. Discuss the questions in the box below that can help in identifying whether a child cannot see at all or see a just little.

Note to the Facilitator:

How to identify visual impairment or blindness:

If you are unsure whether a child (at least) has some degree of sight, watch to see:

- *Does he closed his eyes in bright sunlight or turn her head toward a light?*
- *Does he bring objects close to his eyes?*
- *Does he follow slowly moving objects with his head?*
- *Does he always tilt his head in a certain way?*
- *Does he reach for objects that do not make sounds?*
- *Does the baby repeat unusual movement over and over, like poking his eyes, flapping his hands, and rocking his body? (If the answer is yes to the last question, that points to visual problems, maybe blindness)*

5. If you detect blindness or visual impairment, make sure the family seeks a medical assessment as soon as possible from a hospital or specialized clinic, because some forms of visual impairment can be treated medically or helped with assistive devices, such as eyeglasses.

Practice and Discussion: Teaching a blind child to become independent

30 minutes

A. Ask all participants to focus on an object on the other side of the room – they can choose a door, a window, a particular chair, etc. Now, ask them to close their eyes tight, get up, and slowly walk to that object. When they think they have gotten there, they should open their eyes. Ask everyone to reflect on the experience of being blind for a few minutes – What made it difficult? How did they try to make it across the room without falling? Since they couldn't use their eyes, what other senses did they use (e.g. touch, hearing, memory)? If they could get some help crossing the room without sight again, what kind of help would they want?

B. Have everyone return to their original chairs. Explain that you will teach participants several practical things that parents, caregivers and other community members can do – including themselves – to help teach daily-life skills to a child who is blind.

C. Show the below and discuss the eight points that follow. Allow for comments and a brief discussion after each point.

. **Please use Picture 1 in the Annex to illustrate the process of teaching a skill for the child who is blind.**

1. Help a blind or visually impaired child to explore his surroundings. Talk about what you see, and encourage him to touch and hold things.

Note to the Facilitator: Read this aloud:

A child who is blind often repeats unusual movements over and over, like poking his eyes, flapping his hands, and rocking his body. It is probably because every baby needs to explore and play. If he does not know there are interesting things around him, a baby will play with the only thing he knows — his body. You may notice these movements before the baby is 6 months old. These movements may harm his development if they *keep him from paying attention to the people and things around him. Give the child other things to play with – things to touch and hold – to distract him from the repetetive movements.*

2. Encourage the child to touch different kinds of things with an interesting feel and a strong but pleasant smell — like fruits, vegetables, or flowers. If you encourage a child to use his sense of touch, hearing, and smell to find out what objects are like, he will learn more about the world and be able to talk about what he knows.

3. Remember that all children need a lot of practice before they completely learn new skill. First, a child learns to do the skill with help. Then he remembers how to do it all by himself. Finally, he uses the skill in new situations.

Note to the Facilitator: Read this aloud:

For example, when a child is learning to feed himself, at first you may put your hands over his hands and move his arms. As you feel he starts to do some of the activity by himself, loosen your hold on his hand. Then gradually move your hand to his wrist and lower arm and then to the elbow. It may be easier for him to understand your movements if you are behind. But be sure to ask him first if it is okay.

4. Encourage other children in your locality to play together, to support each other.

5. Take the child to different places as much as possible — when collecting water, or gathering wood, or going to the market, or to school, religious services, and community meetings and events. Along the way, describe what you see and encourage the child to listen to sounds, and to touch and smell things. Introduce the child to the people and animals you meet, and teach him how to greet people.

6. **Cover all open wells, ditches, and holes** to make the area outside the child's home safer before the child starts moving by him from place to place. Show the child where these things are and explain what and why they are there. Teach him how to move independently using a white-cane or a stick, i.e. by moving that stick slowly and gently from side to side in front of him, when he walks by herself outside the home.

7. When he is old enough for schooling, make sure the child joins a school that is able to teach him. Find out ahead of time if the child will be better served in a specialized school for the blind (consult Yekokeb Berhan's Directory of Services for Children with Special Needs) or mainstreamed in a school in the child's own locality. Help the child to get the materials he need for education, including the

reading of Braille (a special print using raised dots that blind people can feel). Refer the Special Needs Directory prepared by Yekokeb Berhan to learn how to get braille materials.

8. Introduce the child to adults who are blind or who have a visual impairment but who are successful in life, with a job, an education, a good family life, etc. Ask that person to offer words of encouragement to the child. Above all, help the child see himself as capable, emphasizing all the things that the child CAN DO, so that he can grow up to be an independent adult.

Activity 2.2 UNDERSTANDING A CHILD WHO IS DEAF OR HEARING IMPAIRED (HARD OF HEARING)

(45 minutes)

Discussion: How to identify a child with a hearing impairment

15 minutes

Objective of the Activity

By the end of this activity participants will be able to:

- Detect deafness or or severe hearing impairment in a young child
- Understand the communication barrier that a child who is deaf (or hard of hearing) faces
- Understand the actions to be taken in helping children who are deaf or hard of hearing to be prepared become independent and part of their own community.

Note to the Facilitator:

1. Start by introducing the objectives of the activity. Explain the difference between deafness (not being able to hear at all) and hearing impairment (also called, hard-of-hearing that is being able to hear only partially). Explain that hearing problems can begin at birth or later on in life, following an ear infection, an accident, or an illness.

2. Ask participants how they might detect deafness or hearing impairment in a very young child (give them 3-4 minutes).

3. Explain that – the same as for blindness -- it is common in many communities for families to deny that their child may have some kind of hearing disability, for fear of rejection by the community, or because they lack hope for the child's future. Family members may also not know what to do about the matter. But if a disability is detected early, the child may be able to get medical treatment to improve the situation (sometimes this helps, but not always), and the family can be taught to

provide support that will build on the child’s strengths – on what the child CAN do – and also obtain additional assistance from other organizations or special schools, if needed. This approach is important for all disabilities, not just those involving hearing loss.

4. Discuss the questions in the box below that can help in identifying whether a child cannot hear at all or hear a just little.

Note to the Facilitator:

How to check a child’s hearing at home

If a child can hear a little, finding out which sounds she can hear will help you to decide the kind of support the child needs to get. You will know if a very young child hears a sound because she may:

- *move her arms and legs;*
- *change the look on her face;*
- *become very still;*
- *make a sound herself;*
- *smile or laugh;*
- *turn toward the sound, or tilt her head to listen;*
- *Be startled, open her eyes wider, or blink.*

If you get no reaction at all, even for a loud noise and also a high-pitched noise *that takes place away from the child’s line of vision, it is possible that the child is completely deaf.*

6. If you detect deafness or a hearing impairment, make sure the family seeks a medical assessment as soon as possible from a hospital or specialized clinic, because some forms of hearing impairment can be treated medically or helped with assistive devices, such as a hearing aid. For additional resources and information about special schools for the deaf, check the Yekokeb Berhan Directory of Services for Children with Special Needs.

Practice and Discussion: Communicating with a Deaf or Hard-of-Hearing Child

(30 minutes)

A. This game will help participants understand how difficult it can be for a child who cannot hear at all, or who cannot hear well, to communicate. It also demonstrates the importance of using different methods to effectively interact with deaf children.

B. Divide the participants into pairs. Each member of the pair takes turns trying to say something to the other without using any words or sounds – but the person may use pictures, gestures or facial expressions. The goal is that each person should communicate a message or an idea to the other, who should guess what the message is. Examples are, 'I am sleepy;' 'Give me the ball;' , 'I'm lost and can't find my house;' or 'I had a bad dream.'

C. After trying this for a few minutes, ask the participants to reflect on the experience. Ask, how did it feel? What could the other person have done to make the communication easier?

D. Explain that you will teach participants several practical things that parents, caregivers and other community members can do – including themselves – to improve communication for and with a deaf or hard-of-hearing child. Ask:

- What are the languages a child who is deaf/hard of hearing can learn to communicate with other people?
- How the family and other people can help the child to become involved in everyday life?

E. After hearing the participants' ideas, conclude the activity by presenting the note below.

Note to the Facilitator: Read this aloud:

Once the child's hearing level is identified, the family should work hard to teach her language and focus on her ability. Help the child grow up into a capable and happy adult.

Children who are deaf or cannot hear well can learn one of two different kinds of language. The first of these is called Sign Language, when she uses her hands to communicate, using the agreed-upon signs – one for each word or phrase – that is commonly used by the deaf community in Ethiopia. Ethiopian Sign Language is taught in all schools for the deaf, and also by some other schools or NGOs. The second language is spoken language, when the child uses a combination of what she hears and lip-reading. If the child focuses on the spoken language, she can also – in most cases – be trained to user her own voice to speak.

Some children who are deaf use a combination of lip-reading, facial expressions, hand gestures or sign-language. So when you interact with a child who is deaf or hard of hearing, face the child and speak clearly; also try to use facial expressions and hand-gestures that you believe the child can understand. In addition, you can *also use gentle touch on the child's arm or shoulder to get the child's attention. Show the child how to do something by example, and then have the child do the same. Point to different things to give a child a choice.*

There may be various organizations in your community that can provide support for deaf children and their families. The may be able to provide a hearing aid, teach Ethiopian Sign Language, or help the child meet other deaf children so she does not feel so alone. Refer to the Yekokeb Berhan Directory for Children with Special Needs to find the contact information

A copy of the Sign Language Alphabet for Ethiopia is included as ANNEX FOUR

Activity 2.3: Review - Magic Ball

(10 minutes)

Ask participants to reflect on the main points covered in this session. Ask them to think about an idea or something new that they learned that they would like to share with other participants

Toss a crumpled paper ball to a participant and ask them to share one idea and then toss the ball to someone else until all the participants cover all the main themes. Fill in gaps as necessary.

END OF SESSION TWO

SESSION THREE

Time: Two hours and fifteen minutes

Note that Session three can be further broken down into two sessions – Activity 3.1 and Activities 3.2 – 3.4 – if necessary.)

Activity 3.1 UNDERSTANDING A CHILD WITH AN INTELLECTUAL DISABILITY (A SLOW LEARNER)

Time required: 1 hour.

Objective of the Activity

By the end of this activity, participants will be able to understand:

- What is an intellectual disability?
- How can we help children with an intellectual disability learn new things and feel that they are important members of the family and community?

Discussion: What is an intellectual disability in a child (a slow learner)?

(10 minutes).

Note to the facilitator

1. Start by introducing the objectives of the activity. Explain that an intellectual disability means that the child has difficulty learning – he may be a slow learner, he may forget things easily**.** Explain, too, that an intellectual disability may be **mild** or moderate – meaning that the child will eventually be able to learn most of the things that other children learn, but it will take longer. Or it may be **severe** (also called "profound") and come in combination with other kinds of disabilities – meaning that the child will be able to learn *some* things, but will always be dependent on another person for many activities of daily life.

1) Children with an intellectual disability do not learn as quickly as other children. But still, they CAN and THEY DO LEARN. For example, most children are able to sit up by themselves when they are 6 – 8 months old and start walking when they are 12 – 15 months old. They will also start speaking words soon after age 1, and by the age 2 they will start to say some simple sentences. But for a slow or delayed learner, these things will come later. It may take extra effort, but learning still takes place. It is true however, that if the intellectual disability is severe, the child may never learn some of these things.

2) It is important to remember that children with an intellectual disability have feelings like everyone else. They want to feel worthwhile, they want to feel loved and they want to have an important role in the family. Therefore, you should be prepared to repeat or re-enforce learning for these children, and you should help them focus on the things they can do well – for example, by helping out other family members. It is also important that children with an intellectual disability go to school, wherever possible. This may be in a Special Education class with a teacher who has been trained to work with children who are slow learners. For more information on resources for children with an intellectual disability, check out Yekokeb Berhan's Directory for Children with Special Needs.

Practice and Discussion: Helping a Child with an Intellectual Disability

(20 minutes)

Tell this story and discuss the questions that follow: (5 minutes).

STORY AND DISCUSSION: "I FORGOT"

Berhanu is little boy, age 7, whose mother asks him to go to the corner shop to buy some bananas. He comes back with nothing. The next time the boy goes to buy bananas, he comes back with matches. When the mother asks him why he didn't bring back bananas, Berhanu starts crying and cannot explain what happened.

1. Why is this child so forgetful?
2. How could we help him remember?
3. What do we mean by a child with intellectual disability and what strengths and limitations does he have?

Ask participants if they know of a child who is a slow learner in their community, and how they think that child could be helped.

After hearing the participants' ideas, share some of these recommendations that could help a child like Birhanu remember things.

Ideas to help a child like Birhanu remember things

- Another child could go with the boy — not to buy the bananas, but to help him remember, or to give him clues;
- He could take a picture, some sticks, a banana peel or some other clue to remind him of the number and the type of the goods he has to bring back from the shop;
- Another child/adult could practice with him at home playing games. Start with one thing at a time. Praise or reward the boy each time he remembers and does it right. Do not praise and never punish the child when he forgets. Remember: he has difficulty of remembering. It is not his fault; he may have intellectual disability or be a slow learner...

. Please use Picture 2 in the Annex to for a picture of a child with Down's Syndrome, which is one kind of intellectual disability

Reference for the Facilitator: Refer to this information if needed

Intellectual disability is a type of developmental disability that produces significant limitations in intellectual functioning ability and adaptive behaviors. These limitations result in problems with reasoning, learning or problem-solving as well as communication and social skills difficulties. There are varying degrees of intellectual disability, usually called Mild, Moderate and Severe or Profound.

People with intellectual disabilities can and do learn new skills, but they learn them slowly and it takes extra efforts. It is important to be patient and not to get angry if the child forgets or doesn't understand right away.

There are many different signs of intellectual disability in children. Signs may appear during infancy, or they may not be noticeable until a child reaches school age. It often depends on the severity of the disability.

In children with severe or profound intellectual disability, there may be additional disabilities or health problems as well. These problems may include seizures, mental disorders, motor, vision, or hearing impairments. A person can also have both autism (see below) and intellectual disability.

Most common signs of intellectual disability are:

- Rolling over, sitting up, crawling, or walking late.

- Talking late or having trouble with talking
- Being slow to master things like toilet-training, dressing, and feeding herself
- Having difficulty remembering things
- Being unable to connect actions with consequences
- Having behavior problems such as sudden, explosive tantrums
- Having difficulty with problem-solving or logical thinking.

Some children are born with an intellectual disability; other times it is caused by illness, injury or severe malnutrition. If a child becomes sick with an infection like meningitis, whooping cough, or the measles, or if a child is severely malnourished, it is important to get medial attention right away. Medical treatment in these situations will improve the child's health and can prevent an intellectual disability.

Discussion:
Designing Learning and Early Stimulation Activities
(30 minutes)

A) Pair participants and ask them to discuss on how a child with intellectual disability can be helped to develop life skills such as eating, talking, dressing, toileting…
B) Share the points under facilitator's note with participants.
C) While you read each point ask them to share their experiences if they apply the activity with the child they care and their successes.

Note for the Facilitator:

EARLY STIMULATION STEPS

1. Decide what a skill to teach and **divide each new skill into small steps**: activities the child can learn in a day or two, and then go on to the next step.
2. **Be patient and observant.** Children do not learn all the time; sometimes they need to rest. Try to understand how she thinks, what she knows, and how she uses her new skills. You will then learn how to help her practice and improve those skills.

3. **Talk a lot to the child. Using clear, simple words**, say everything that you do with her. A child listens to and begins to learn language long before she begins to speak. Although it may seem as though she does not understand or respond, still talk to her a lot. If you think she does not hear, talk to her but also use ‘sign language’. Make sure she looks at you as you speak.
4. When you are helping a child learn a new skill, **guide the child’s movements with your hands.** It usually works better to gently guide the child than to tell her how to do something. If she tries to do something but has difficulty, guiding her hands so that she is successful will make her a lot more eager to learn the skill than if you say “NO — do it like this! “For example to teach a child to bring her hands to her mouth (or to eat by herself) you can, help her put her finger in a food she enjoys, and then to put her finger in her mouth. After the child has learned to do this, let her do it by herself.
5. **Use a mirror to help the child learn about her body** and to use her hands. The mirror helps the child see and recognize parts of her body. It is especially useful for children who have difficulty relating to different parts of their body or knowing where they are. This can happen in some forms of intellectual disability, cerebral palsy, spinal cord injury, and spina bifida).
6. **Use imitation (copying).** To teach a new action or skill, do something first and encourage the child to copy you. Turn it into a game. Many children with developmental delay (especially those with Down syndrome) love to copy or imitate the actions of others. This is a good way to teach many things, from physical activities to sounds and words.
7. Encourage the child to **reach out or go for what she wants**. Even at early stages of development, it is a mistake to always place in her hands what a child wants. Instead, use the child’s desire as a chance to have her use her developing body skills and language skills to get what she wants — by reaching, twisting, rising, creeping, or whatever she is learning to do.
8. **Praise the child a lot.** Praise her, hug her lovingly, or give her a little prize when she does something well (or when she makes a good effort). Praising success works much better (and is much kinder) than scolding or punishing failure.

Activity 3.2 UNDERSTANDING AND RESPONDING TO OTHER FORMS OF DISABILITY

(55 minutes)

Introduction: What other kinds of disability are there?

(5 minutes)

A. Ask participants if they know of any children who have a different kind of disability (not related to sight, hearing or an intellectual disability).

B. List these (or describe these) on a flip chart. Participants may refer to:

- Difficulties with walking or movement,
- Problems with speech or social interactions,
- Spasticity or spasms (when the muscles tighten and are not flexible) and
- Occasional seizures – when a child suddenly falls down, crumples up and makes strange sounds.
- Physical and mental impairments caused by untreated illnesses, such as HIV and AIDS

C. Explain that it is not important for participants to name all of the different disabilities, nor to know how to respond or treat each one. But it IS IMPORTANT to recognize the main ones and to seek medical help when a problem first surfaces. It is also important provide ongoing support to both the child and her or his family.

Small Group Work and Discussion: Focusing on Four Additional Conditions that can cause Disability

(50 minutes)

Divide the participants into five groups, and assign each of them one of the conditions described below that can cause disability:

A) Brain disorders, such as Autism; B) Epilepsy; C) Cerebral Palsy;
D) Conditions related to HIV and AIDS, and E) Clubfoot.

Give each group a copy of the explanation below for these five conditions and tell them that they have 12-15 minutes to read among themselves and prepare a short presentation (4-5 minutes in length) to the rest of the group about the condition.

After the presentations are made, hold a short, concluding discussion.

A) What about brain disorders, such as Autism?

Our brains are very complicated – and even the most famous scientists in the world are still learning new things about how it functions.

For most of us, our brain is an amazing part of our body, and we are constantly able to learn new information and new skills. But not everyone's brain works in the same way.

We have already learned that people with intellectual disabilities can and do learn new skills, but they learn them more slowly. For some other people, however, the brain functions very well in some ways, but poorly in others. The reasons vary – some people are born that way, or else this type of brain disorder is the result of an accident or illness. Caring for someone with a brain disorder requires a lot of time and patience, so caregivers usually welcome extra support from family members, volunteers and friends. Medications are available to help reduce the symptoms with some kinds of brain disorders, so caregivers should seek help from a hospital or specialty clinic.

Autism:

Autism is a lifelong condition that makes it difficult for children to communicate with other people. It also affects how they understand or make sense of the world around them. The condition affects different children in different ways. Scientists don't know the exact cause of autism, but children who have autism are born with the condition.

Children with autism may experience over-sensitivity or under-sensitivity to sounds, touch, tastes, smells, light or color.

- For example, they may enter a room where people are talking normally, but to them it sounds like everyone is shouting very loud -- something that is so painful for them that they will want to cover their ears or run someplace else.
- Children with autism often have difficulty socializing with people; they may not want to be touched or come physically close to another person. Remember: They do not choose these reactions; it is just how their brains work.

It is important to understand these reactions and not blame the child; instead you should try to understand why someone with autism acts in a certain way. Children with mild autism can go to a normal school, but children with severe autism may need special help.

In Ethiopia, there are organizations that can advise parents and other caregivers about autism. See Yekokeb Berhan's Directory of Services for Children with Special Needs for contact details. By way of example, three organizations that focus on Autism and intellectual disability are:

2. Association on Intellectual Disability at 011-6-63-18-66
3. Nehemiah Autism Center at 0930-01-26-52
4. Joy Center for Children with Autism at 0113-20-61-60.

B) What is Epilepsy?

Epilepsy is a medical condition in which seizures – that is, brief, abnormal electrical activity in the brain -- cause involuntary body movements, sensations, behaviors or awareness. There is no relationship between epilepsy and an evil spirit. Also, smelling fire does not help to bring back the child's conscious.

It is important to seek medical help from a doctor who knows about epilepsy, for example at a hospital or specialized clinic. For most people affected by epilepsy, medical treatment, including prescription drugs, can effectively control the condition as long as the drugs are taken correctly -- as directed by the doctor or nurse. If there are side effects or if the medication is not effective, speak to the doctor to see if another medication could be tried that can improve the situation.

What to do for an Epileptic Seisure:

If you are present when someone has an epileptic seizure, remove all hard or sharp objects that are near that person, which could cause the person to accidentally hurt herself. If you can, loosen clothing around the person's neck, but do not try to hold her down or restrain her. After the seizure is over, let the person relax. She or he may be confused and not remember what just happened. You may speak softly and use gentle touch to help re-orient and comfort the person. Seek medical assistance, where possible.

Consider getting counseling for children with epilepsy if they appear uninterested in friends, school or normal activities; or if they exhibit excessive anger, poor self-esteem or lack of self-control.

C) What is Cerebral Palsy?

Cerebral palsy affects the body's movement and position due to a paralysis in the brain that happened before the baby was born, at birth, or as a baby. Except for drugs to control seizures (which sometimes accompanies Cerebral Palsy), medicines usually do not help. However, regular movement and physical therapy can improve the body's condition... The earlier we start, the more improvement can be made.

About half of the children with cerebral palsy also have an intellectual disability , but this also means that about half the children with cerebral palsy have a normal intelligence and should attend a regular school.

Most children with cerebral palsy can lead a thriving and happy life if they get their family's dedication and positive thinking. The damaged parts of the brain cannot be repaired, but often the child can learn to use the undamaged parts to do what she wants to do

Please use Picture 3 in the Annex to illustrate the different parts of the body that may be affected by Cerebral Palsy

Signs of Cerebral Palsy

1) **Slow development:** compared to other children in the village, the child is slow to hold up her head, to use her hands, to sit, or to move around.

2) **Challenge in Feeding:** the baby may have difficulties with sucking, swallowing and chewing. She may choke or gag often.

3) **Weak muscles:** her body may stiffen when she is carried, dressed, or washed, or during play. Later she may not learn to feed or dress herself, to wash, use the toilet, or to play with others. This may be due to sudden stiffening of the body, or to being so floppy she 'falls all over the place'. The baby may be so limp that her head seems as if it will fall off. Or she may suddenly stiffen like a board, so that no one feels able to carry or hug her. Her faces twist, or may drool because of weak face muscles or difficulty swallowing. Hearing and sight are also sometimes affected. Observe the child carefully and test her to find out how well she can hear

and see.

4) **Communication difficulties:** the baby may not respond or react as other babies do. This may partly be due to floppiness. Stiffness or lack of arm gestures, or control of face muscles. The child may also be slow in beginning to speak. Later some children develop unclear speech or other speaking difficulties. Although parents find it hard to know exactly what the child wants, they gradually find ways of understanding many of her needs.

5) **Seizures:** epilepsy fits, and convulsions occur in some children with cerebral palsy.

6) **Restless behavior:** sudden changes of mood from laughing to crying, fears, fits of anger, and other difficult behavior may be present.

7) **Abnormal reflexes and trouble in controlling movements** of their bodies: Babies have certain 'early reflexes' or automatic body movements that normally go away in the first weeks or months of life. However, these are only important if they affect how the child moves. Knee jerk and other tendon-jump reflexes are usually over-active (jump higher than normal).

D) What about conditions related to HIV and AIDS?

Some illnesses – if not diagnosed (tested) early and properly treated – can lead to a disabling conditions or even death. This includes malaria, tuberculosis, meningitis and HIV and AIDS. (For example, if someone with HIV is not treated, the person will become vulnerable to different types of infections that will make the person very weak, possibly also affecting the brain.)

Therefore, whenever a child is seriously ill or if an illness lasts longer than a few days, the child should be taken to a clinic or hospital for testing or treatment. It is also important to make sure that all children under the age of five get all of their vaccinations, as this can help prevent certain illnesses that can cause disability (for example, polio).

The Yekokeb Berhan program places a special focus on preventing the spread of HIV and AIDS, and also caring for people who are already infected with the HIV virus – while working to eliminate stigma and discrimination. Here are four questions and answers that everyone should know.

(1) What can we do to identify all HIV+ children and adults (before they get frightfully sick)?

Use our annual CSI assessment *that contains specific questions on HIV testing and treatment*

Make more referrals :

For testing with Health Centers:

- *to prevent the transmission of the HIV virus from mother-to-child,*
- *for people who show weakness or repeated illness*
- *for children who appear weak and easily become ill*

For treatment of HIV and AIDS through the Health Center

For related support services that the government provides to HIV-affected families

(2) How can we better prevent the spread of HIV, promote care and treatment and reduce stigma, while protecting confidentiality?

Reducing stigma, preventing the spread of HIV and protecting a person's confidentiality (privacy) often requires a change in behavior and attitudes—toward acceptance, respect and equitable treatment. This can be done one-on-one during volunteer home-visits and through group discussions, such as:

- *Life skills for teens;*
- *Inviting a Health Extension worker to a CSSG meeting or for a Community Conversation*

(3) How can we better support HIV+ children and/or their HIV+ caregivers?

- Give priority for HIV+ Children
- Give more support to HIV+ Caregivers
- Make referrals for HIV testing and promote the Coordination of Care
- Facilitate disclosure within the family or with health care workers
- Respect confidentiality (not telling others) without the family's permission

(4) How should we respond to HIV+ children in our catchment area who are not yet beneficiaries?

Although generally we are not able to expand our caseload (other than small variations), we recognize that as a PEPFAR funded program, priority should be given to children with HIV and AIDS.

E) What is Clubfoot?

About 3 out of 1,000 children are born with a clubfoot (their feet turn inward). Clubfoot is a general term used to describe a range of unusual positions of the foot. You may see any one of the following characteristics and each one may vary from mild to severe:

- The foot (especially the heel) is usually smaller than normal.
- The foot may point downward.
- The front of the foot may be rotated toward the other foot.
- The foot may turn in, and in extreme cases, the bottom of the foot can point up.

Most types of clubfoot are present at birth (congenital clubfoot). Clubfoot can happen in one foot or in both feet. In almost half of affected infants, both feet are involved.

Clubfoot can be mild or severe and all cases require treatment. Clubfoot will not resolve without treatment.

Although clubfoot is painless in a baby, treatment should begin immediately. Clubfoot can cause significant problems as the child grows. But with early treatment most children born with clubfoot are able to lead a normal life. If only the front part of the foot is affected (not the heal), then special exercises may help. It is important to consult a health worker as soon as possible, to determine what kind of treatment is the best option.

. **Please use Picture 4 in the Annex to illustrate the “before” and “after” examples of Club Foot**

Non-surgical forms of treatment include strapping, a series of casts and physical therapy (special exercises) – each depending on the situation. These do not hurt the child and have no negative side effects. Surgical treatment is complicated, often expensive and may not be as successful – therefore the non-surgical forms of treatment are always preferred.

Correction of clubfeet should begin soon after the child is born. The younger the child – even a few days old – the easier it is to correct this condition. In an older child, it takes longer, and surgery is more often needed for good, lasting results.

Sometimes children with clubfoot also have another disability, for example related to the spine. Once again, this is why it is very important to consult a health worker if you suspect a child is born with clubfoot.

There are several special clinics in Ethiopia that provide strapping or casting treatment for children with clubfoot, and these are free-of-charge. Yekokeb Berhan's Directory of Services for Children with Special Needs Services should be consulted for more information.

Activity 3.3 WORKING TO ELIMINATE STIGMA AND DISCRIMINATION

(10 minutes)

One of the biggest barriers facing people with a disability or illness – including but not limited to HIV and AIDS – is stigma and discrimination. This happens when people are defined by their condition (for example, "The disabled person" or "the HIV-positive child") or treated unfairly or with fear. For some people, stigma and discrimination is the worst part of their illness, condition or disability.

Note to the facilitator: In this short discussion, ask participants to define stigma and discrimination (as they understand it) and then ask them for suggestions of how it can be prevented, reduced or eliminated. Write this information on a flip-chart. Refer to the box below, if needed.

HOW TO REDUCE STIGMA AND DISCRIMINATION

(For people living with HIV & AIDS, or with other condition and disabilities)

STIGMA is a form of prejudice that spreads fear and misinformation. It labels individuals and perpetuates stereotypes.

Reducing stigma requires a change in behavior and attitudes—toward **acceptance**, **respect** and **equitable treatment**. Suggestions include:

- Accept the individual as a person first – not as someone who is defined by the condition or disability
- Never single out the individual publicly or disclose (give out) information about the condition without that person's permission
- Respect the person's rights, feelings and opinions
- Treat the person like you want to be treated.
- Educate yourself and others about the condition or disability. This will reduce fear and misunderstanding.

- Work to change discriminatory or stigmatizing policies, attitudes or actions that you see in others.

Activity 3.4: Review - Magic Ball

(10 minutes)

Ask participants to reflect on the main points covered in this session. Ask them to think about an idea or something new that they learned that they would like to share with other participants

Toss a crumpled paper ball to a participant and ask them to share one idea and then toss the ball to someone else until all the participants cover all the main themes. Fill in gaps as necessary.

END OF SESSION THREE

SESSION FOUR: ESTABLISHING A COMMUNITY CARE SYSTEM

Objective of the session:

By the end of this session, participants will be able to:

- Understand the importance of providing additional help to parents and other caregivers who have a child with a serious disability or with multiple disabilities;
- Plan and undertake specific measures to support families who have children with disabilities, so that the children can reach their greatest potential;
- Involve others in mobilizing community support and referrals to assist these children and their families.

Materials required: flip chart and markers, and color cards. Have at least one copy on hand for the group exercises (Activity 3.3) of:

- Yekokeb Berhan's "Directory of Services for Children with Special Needs" (English or Amharic)
- Yekokeb Berhan's "How to Start and Run a Support Group." (English or Amharic)

Time Required: One hour and 50 minutes.

Introduction to Caring for the Caregivers

When children have a combination of severe disabilities, we say they are 'multiply disabled - The combinations may include any of the specific disabilities we have already reviewed, or there may be another condition involved. Generally, children with multiple disabilities face the most challenges, and often they cannot be accommodated in local schools or even special schools. Children with severe disabilities, or with multiple disabilities, usually require the most assistance. Family members often cannot handle these themselves; they need additional support and assistive devices (for example, a wheelchair). . And even the most loving and dedicated parents, after months and years of continuously caring a severely disabled child, need to take a break. In this session we will try to identify some of the steps that you can take to care for the caregivers – that is, to help those parents and caregivers in supporting a child with severe or multiple disabilities.

Activity 4.1: Case Story.

(10 minutes)

CASE STORY: Read this aloud:

Some time ago, Yekokeb Berhan's Senior Technical Advisor, Dr. Lucy visited a town where the volunteers wanted her to see a 16 year-old boy with multiple disabilities called Sule. The sun was very hot as they walked, but finally they reached the youngster who was sitting by himself under a shaded roof – his leg tied with a chain to a post, like a dog's. Sule appeared blind and intellectually disabled -- among other problems -- but responded with a big smile when the Senior Technical Advisor started stroking his head. When Dr. Lucy gave Sule a folded paper toy she made, he held it carefully and examined it with his hands from all angles.

When seeing this, Dr. Lucy's first thought was that Sule's parent or guardian must be very cruel to allow this situation. But when she asked about the caregiver, other information emerged. She learned that Sule's parents died some years ago, and now he lived in the care of an older sister. They were very poor and the older sister had to spend some hours every day at the market, in order to earn a few Birr. She used to let Sule wander around the neighborhood during the day, but some months ago another child drowned in a nearby river and the older sister was afraid that the same could happen to Sule. No one in the community offered to help, so tying him under the shade every day for a few hours was the only option that Sule's sister felt she had.

Dr. Lucy became very sensitive to the condition of Sule's sister and all the other caretakers of children with multiple disabilities. She wondered: what could be done to help BOTH Sule and his older sister, and others like them?

(Allow for some reaction and discussion among participants, before moving on to Activity 4.2).

Activity 4.2: Imagining the help that Parents and Caregivers Need.

(30 minutes)

Divide the participants into groups of two or three. Ask them to imagine that they are the parent of a severely disabled child or a multiply disabled child. Ask the group to list the different kinds of support they think they would need in order to care for this child in the best way possible. Give the groups 5 minutes to list as many different kinds of support they can think of and then list these on the flip chart.

Note to the Facilitator: Read this aloud:

(If the participants have not identified the following, be sure to add these):

- Access to good medical care (health services) that can provide whatever treatment might be available
- Access to organizations and people who can advise me about the condition(s) my child has, and what can be done to help the child as much as possible.
- Access to religious leaders – for example, a priest or imam – who will provide comfort and guidance (not pass on blame or stigma), and who will emphasize that God loves all children, including mine.
- Access to assistive devices that might help – for example, a wheelchair, eyeglasses, etc.
- Regular visits by volunteers, who can show me how to stimulate my child, to help improve his learning and his ability to move his body.
- Emotional support and inclusion in community activities – for both me and my child
- Contact with other parents or caregivers who are facing some of the same challenges as I am.
- Access to a day care center for a few days or even a few hours a week, where my child would be with other children like himself. During this time I could earn some money or participate in other activities in the community.

After the different ideas are listed and discussed, ask which kinds of support the participants think that they can help with, either by providing the support themselves or helping to find someone else who can. Put a check-mark or star next to those where the participants said that they could play a helpful role.

Activity 4.3: Three Things You Can Do to Start or Strengthen a Community Care System

(1 hour)

In this activity, we will focus on three of the ideas that were mentioned, that can help parents and other caregivers of a severely disabled or multiply disabled child.

Divide the participants into three groups. Give each group one of the ideas below and ask them to put together a short ROLE PLAY for the group – 5-7 minutes each – that will explain their idea. The groups have 15 minutes to prepare their Role Play.

After each group performs their Role Play, allow 2-3 minutes for questions. At the end of the role plays, briefly conclude the discussion by highlighting some common themes.

IDEA #1: START A SUPPORT GROUP OF PARENTS WORKING TOGETHER

(For this role play, you should demonstrate the steps involved, in starting a support groups of parents and caregivers of children with severe or multiple disabilities.) And also explain the benefits of participating in a support group.

These are the ideas to consider in preparing the role play.

Explain that participating in a support group with other parents and caregivers of children with disabilities can help in many ways. Working together can provide an opportunity to:

- ☐ Share feelings and information
- ☐ Give each other ideas about activities to help the children and the best ways to adapt activities for a particular child
- ☐ Work together to make the community more friendly, safe, and supportive for children with disabilities.

To start a support group:

1. Find 2 or more parents or caregivers who want to start a group. If you do not know other parents/ caregivers whose children have a disability, you may want to include adults with disabilities, friends, community workers and others. A health worker may know of parents in nearby communities.
2. Plan when and where to meet. It helps to find a quiet place, like a school, health post, cooperative, or place of worship.
3. At the first meeting, discuss why you are meeting and what you hope to do. Probably one person will be the leader of the first few meetings. But it is important that no one person makes decisions for the group. Everyone should have a chance to talk, but try to keep the discussion focused on the main reasons for the meeting. After the first few meetings, take turns leading the group. Having more than one person lead each meeting will help to share responsibilities among the groups.
4. Refer to the Yekokeb Berhan booklet on, How to Start and Run a Support Group for more information. (The booklet is available in English and Amharic.)

IDEA #2: PROVIDE IN-HOME SUPPORT AND REFERRALS FOR CHILDREN WITH DISABILITIES AND THEIR CAREGIVERS

Yekokeb Berhan has a variety of training materials, resource books, and a Directory of Services for Children with Special Needs (in English and Amharic) that can help volunteers, CC (or CCC) members, and Implementing Partner staff provide guidance, referral, emotional support, and follow-up to children affected by disabilities.

1. This group should briefly act out and explain the following things that volunteers can do:

2. During her regular home-visits, the volunteer can provide supportive counseling, positive stimulation and emotional comfort to the child and his parent or caregiver.

3. If a medical assessment is needed, or a referral to a special school or organization that can may be able to help the child, depending on her or his specific need, the volunteer can work with CC (CCC) members or Implementing Partner staff to access that resource through Yekokeb Berhan's Directory of Services for Children with Special Needs

4. The volunteer can spend time in the home with the child, or arrange for others to do the same, so that the parent/ caregiver can take some time off, go to the market and/or attend to other needs.

5. The volunteer can help the child join with other children in the neighborhood as much as possible, for example for play, in the church or mosque, or at community events.
6. The volunteer can work with local providers – most importantly the local school -- to make sure that the child has access to educational opportunities, to the extent possible for that child. It is understood that inclusion for education may mean some accommodation by the school, for example to move the child's classroom to the ground floor, or assign other children to help the child with the disability get to and from the school, etc.

IDEA #3: PLAN AND FACILITATE A COMMUNITY CARE NETWORK (that is, a CC/CCC subcommittee that focusing on supporting children and adults with disabilities in the community.))

(For this role play, you should demonstrate the steps involved, in starting a community care network, comprised of interested community members.)

Step 1: Ask a group of interested community members – maybe forming a subcommittee of a CC or CCC – to join the group for the training and reflect on the idea of establishing a small sub-committee for helping children with multiple disabilities. The objective of this sub-committee is to provide a network of information and specialized resources, and to facilitate support and the coordination of care, for local children with disabilities and their families.

Step 2: Invite a professional from the Bureau of Women, Children and Youth Affairs, the local Health Post, the Office of Labor and Social Affairs or a Disabled Persons Organization to help the sub-committee to plan and start the process of mobilizing the community to achieve their objective.

Step 3: Give these individuals a piece of paper and ask them to write down what they can personally contribute by way of time, knowledge, skills, or other resources, that could help children with disabilities and their families. (This information is important to have, even if all the CCC or CC members do not end serving in the sub-committee.)

Step 4: Capture the promises on a Flip chart, without repeating the points.

Step 5: Establish a sub-committee of 3-5 persons that can create and coordinate the process of establishing a care system in their community. Sub-committee members should come together and decide a meeting date and venue to start their work.

Step 6: Decide on an Action Plan – what does the sub-committee what to do first, then second, then third? Who should take the lead and what is the time-line?

Step 7: conclude this role play by thanking everyone for their participation and commitment to contribute for their community's development.

Activity 3.4: Review - Magic Ball

(10 minutes)

Ask participants to reflect on the main points covered in this session. Ask them to think about an idea or something new that they learned that they would like to share with other participants

Toss a crumpled paper ball to a participant and ask them to share one idea and then toss the ball to someone else until all the participants cover all the main themes. Fill in gaps as necessary.

END OF SESSION FOUR

(end of the training)

ANNEX ONE: INFORMATION HANDOUTS FOR PARTICIPANTS

Note to the Facilitator:
If it is not possible to reproduce copies of these hand-outs for every volunteer, then each volunteer group should select one or more "Keepers of these Materials," who would bring them to meetings and make sure they are available for other volunteers if requested.
For every packet with Annex One, add the pictures in Annex Three.

1. BLINDNESS

Finding Out If a Child Is Blind And How To Help The Child Prepare For Independent Living

It is always important to identify whether the child is totally blind, or can see a little? If you are unsure whether your child has some degree of sight, watch to see:

- Does she closed her eyes in bright sunlight or turn her head toward a light?
- Does she bring objects close to her eyes?
- Does she follow slowly moving objects with her head?
- Does she always tilt her head in a certain way?
- Does she reach for objects that do not make sounds?
- Does the baby repeat unusual movements over and over, like poking her eyes, flapping her hands, and rocking her body?

Once the family knows how little the child can see or cannot see, the family has to work hard in Helping him see himself as capable, and have a realistic attitude about blindness and grow up to be an independent adult. Consider these points:

1. Help your child to explore his surroundings. Talk about what you see, and encourage him to touch and hold things. If you encourage a child to use his sense of touch, hearing, and smell to find out what objects are like he will learn more about the world and be able to talk about what he knows.

2. Teach him how to move independently using a white-cane or a stick.

3. When he is old enough for schooling, make sure he joined school in his own locality. Help him to get the materials he need for education and learn reading braille. Refer the special needs directory prepared by Yekokeb Berhan to know

how to get braille materials. There are various adaptive technologies for blind persons and helping him to access them will facilitate his independent living.

2. DEAFNESS

Finding out the hearing Level of the Child and How to Help The Child Prepare for Independent Living

It is always important to identify whether the child is totally blind, or can see
If your child can hear a little, finding out which sounds she can hear will help you to decide the kind of support the child needs to get. You will know if your child hears a sound because she may:

- move her arms and legs;
- change the look on her face;
- become very still;
- make a sound herself;
- smile or laugh;
- turn toward the sound, or tilt her head to listen;
- Be startled, open her eyes wider, or blink.

Once the child's hearing level is identified, the family should work hard to teach her language and focus on her ability. Help her to grow up as capable and happy adult.

The 2 kinds of language a child who is deaf or cannot hear well can learn are sign language, when she uses her hands to communicate with the signs used by the deaf community or spoken language, when she uses her voice and lip reading.

3. INTELLECTUAL DISABILITY

Finding out if the Child has an Intellectual Disability and How to Help The Child Prepare for Independent Living

Intellectual disability is a type of developmental disability that produces significant limitations in intellectual functioning ability and adaptive behaviors. These limitations result in problems with reasoning, learning or problem-solving as well as communication and social skills difficulties. There are varying degrees of intellectual disability. But the most common are: Mild, Moderate and Profound intellectual disabilities. People with intellectual disabilities can and do learn new skills, but they learn them slowly. There are many different signs of intellectual disability in children. Signs may appear during infancy, or they may not be noticeable until a child reaches school age. It often depends on the severity of the disability. In children with severe or profound intellectual disability, there may be additional disabilities or health problems as well. These problems may include seizures, mental disorders, motor, vision, or hearing impairments. A person can also have both autism and intellectual disability.

Most common signs of intellectual disability are:

- Delayed development, for example: Rolling over, sitting up, crawling, or walking late.
- Talking late or having trouble with talking
- Slow to master things like potty training, dressing, and feeding himself or herself
- Difficulty remembering things
- Inability to connect actions with consequences
- Behavior problems such as explosive tantrums
- Difficulty with problem-solving or logical thinking.

What is Autism?

Autism is a pervasive developmental disorder (PDD) that affects brain development primarily in communication, language development, and social skills. Since autism and intellectual disability share similarities, diagnosis is sometimes difficult in early childhood. The shared symptoms of autism and intellectual disability can include the following:

- Early childhood developmental delays
- Limited speech and vocabulary
- Problems understanding verbal instruction and following directions
- Learning difficulties
- Attention problems
- Difficulty communicating with peers
- No pretend play
- Needs life skills training and assistance with self-care and safety
- Echolalia or repeating words and phrases out of context
- Repetitive behavior or stemming activities for self-stimulation, such as hand flapping or rocking back and forth
- Sensory processing issues, which can result in an unusual reaction to a taste, smell, sight or sound.

Despite the similarities between autism and intellectual disabilities, there are a number of important differences between autism and intellectual disability. The following are some of the differences:

- A person with intellectual disability develops and performs slower than his peers but he gains skills at an even pace. A person with autism's progress may not be so clear cut. The autistic person may make progress in some areas easily but has difficulties with skills, such as language, communication and social interaction.
- Intellectual disability may present speech and vocabulary challenges but not to the same degree as a case of severe autism, which can render someone nonverbal.
- A person with autism may experience mind-blindness or appear to lack empathy for others because of problems understanding the emotions and emotional responses of others. Mind-blindness is not as common in intellectual disability.
- In some cases a person can recognize intellectual disability by seeing while this is not possible in the case of autism.

To get more information and assistance for children with cognitive disability, contact

1. Association on Intellectual Disability at 011-6-63-18-66
2. Nehemiah Autism Center at 0930-01-26-52
3. Joy Center for Children with Autism at 0113-20-61-60.

What is Cerebral Palsy?

Cerebral palsy is a type of disability that affects movement and body position due to brain paralysis that happened before the baby was born, at birth, or as a baby. Infections of the mother while she is pregnant, differences between the blood of mother and child, lack of oxygen (air) at birth, very high fever, brain infections (meningitis, encephalitis) can be some of the causes for cerebral palsy.

except for drugs to control seizures, medicines usually do not help. Once damaged, the parts of the brain do not recover, nor do they get worse. However, the movements, body positions, and related problems can be improved or worsened depending on how we treat the child and the extent of the injury. The earlier we start, the more improvement can be made. About half of the children with cerebral palsy are developmentally delayed, but this should not be decided too soon.

See Annex, Picture 3 for more information.

Signs of Cerebral Palsy

1. Slow development: compared to other children in the village, the child is slow to hold up her head, to use her hands, to sit, or to move around.

2. Challenge In Feeding: the baby may have difficulties with sucking, swallowing and chewing. She may choke or gag often.

3. Weak muscles: her body may stiffen when she is carried, dressed, or washed, or during play. Later she may not learn to feed or dress herself, to wash, use the toilet, or to play with others. This may be due to sudden stiffening of the body, or to being so floppy she ‘falls all over the place’. The baby may be so limp that her head seems as if it will fall off. Or she may suddenly stiffen like a board, so that no one feels able to carry or hug her. Her face twist, or may drool because of weak face muscles or difficulty swallowing. Hearing and sight are also sometimes affected.

4. Communication difficulties: the baby may not respond or react as other babies do. This may partly be due to floppiness. Stiffness or lack of arm gestures, or control of face muscles. The child may also be slow in beginning to speak. Later some children develop unclear speech or other speaking difficulties. Although parents find it hard to know exactly what the child wants, they gradually find ways of understanding many of her needs.

5. Seizures: epilepsy, fits, and convulsions occur in some children with cerebral palsy.

6. Restless behavior: sudden changes of mood from laughing to crying, fears, fits of anger, and other difficult behavior may be present.

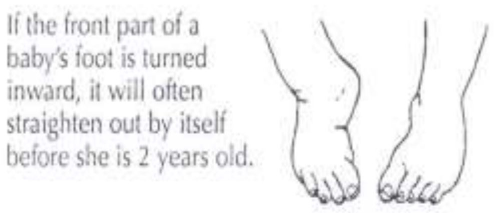
7. Abnormal reflexes and trouble in controlling movements of their bodies: Babies have certain ‘early reflexes’ or automatic body movements that normally go away in the first weeks or months of life. However, these are only important if they affect how the child moves. Knee jerk and other tendon-jump reflexes are usually over-active (jump higher than normal).

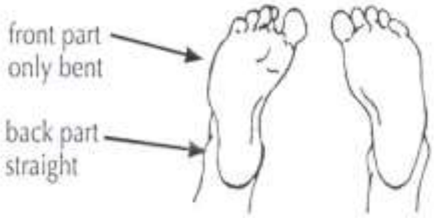
   Ask Yekokeb Berhan staffs for mentoring to develop skill on how to help a child with cerebral palsy.

4. CLUBFOOT

Finding out if the Child has a clubfoot and How to Help The Child Prepare for Independent Living

What is Clubfoot?





About 3 out of 1,000 children are born with a clubfoot (their feet turn inward), usually the cause is unknown. Sometimes a newborn baby's feet turn inward, just because they were in that position in the mother's womb. If the front part of a baby's foot is turned inward, it will often straighten out by itself before she is 2 years old. If you can easily straighten the foot, and bend it into a position opposite to the way it was turned, the foot probably does not have a bone deformity and will get better by itself. The feet may also gradually become deformed into a clubfoot' position, because of cerebral palsy, polio, arthritis, or spinal cord injury. Rarely, clubfeet occur together with a clubbed hand' or other impairment of the body.

See Annex, Picture 4 for more information

There are 3 different ways to correct clubfoot: strapping, casts or surgery. About 60% of clubfeet can be effectively straightened without surgery in 6 to 8 weeks, using either strapping or casts. Correction of clubfeet should begin soon after the child is born — if possible, in the first 2 days while, the baby's bones and joints are still soft. Usually, good correction without surgery is only possible in the first year of life. If the deformity is not severe, however, a clubfoot can sometimes be corrected with casts, even if the child is already 2, 3, or even 5 years old or more. But in an older child, it takes longer, and surgery is more often needed for good, lasting results. There are many clinics that provide strapping or casting treatment for children with clubfoot. Consult a health worker immediately if you think a child is born with clubfoot.

Refer the directory on Special Needs Services prepared by Yekokeb Berhan Program for information on hospitals that correct clubfoot through surgery.

ANNEX 2: REFERENCES

Ethiopian National Disability Action Network, (2010) “Training Guide, Teaching Aid Preparation”, Addis Ababa, Ethiopia.

Ethiopian National Association of Intellectual Disability (2013), Addis Ababa, Ethiopia;

“Respectful Disability Languages.” Mobility International, USA (no author/ date)

Niemann Sandy, and Jacob Namita (2004) “Helping Children Who Are Blind, Family and community support for children with vision problems”, Published by The Hesperian Foundation, Berkeley, California, USA.

Niemann Sandy, Greenstein Devorah and David Darlena (2004) “Helping Children Who Are Deaf, Family and community support for children who do not hear well “ Published by The Hesperian Foundation, Berkeley, California, USA.

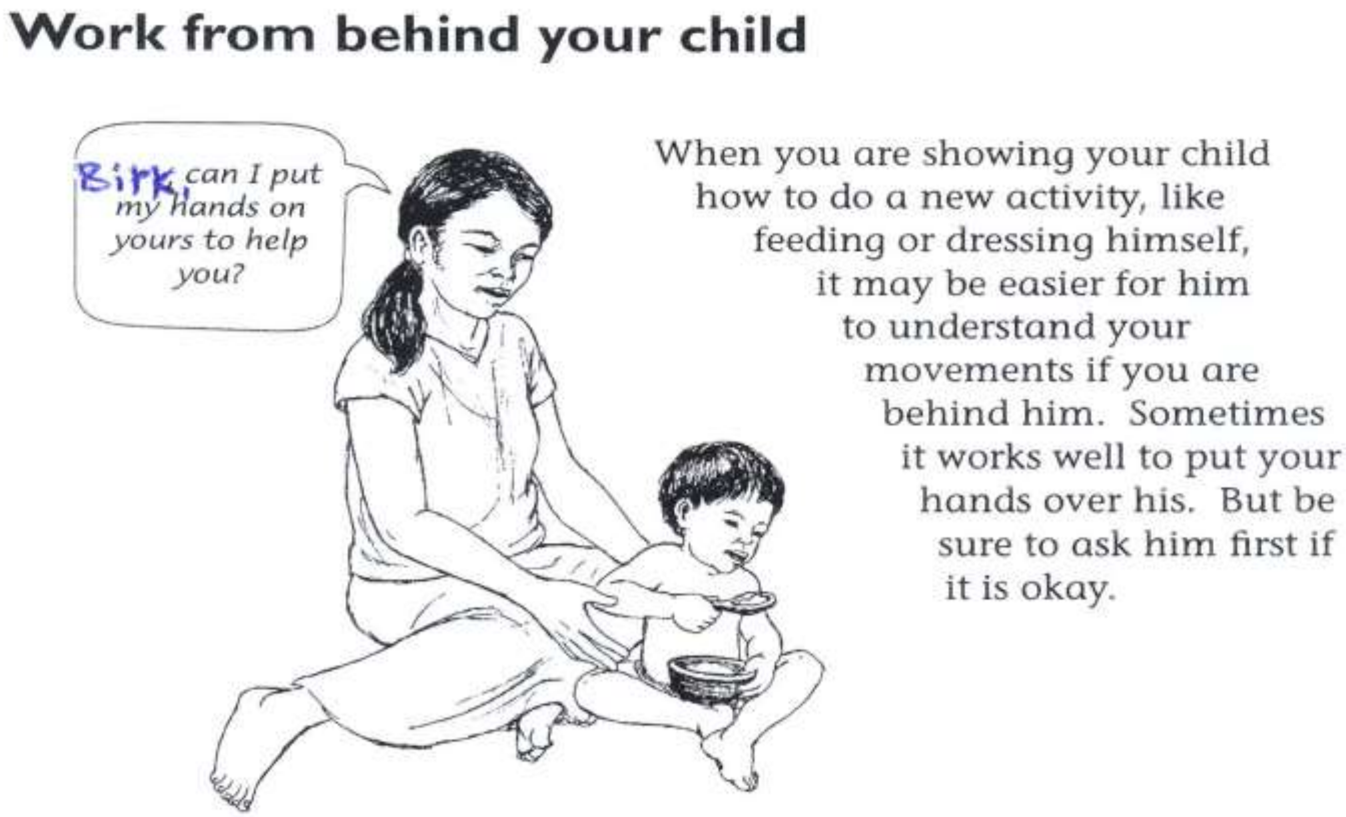
Shared Symptoms of Autism and Intellectual Disability Available at (http://autism.lovetoknow.com/diagnosing-autism/shared-symptoms-autism-mental-retardation)

Werner David (2009) “Disabled Village Children: A guide for community health workers, rehabilitation workers, and families (2nd edition)” Published by the Hesperian Foundation, USA.

Yekokeb Berhan Program for Highly Vulnerable Children (2013, revised), “Directory of Services for Children with Special Needs.” Pact, Addis Ababa, Ethiopia.

ANNEX THREE: PICTURES

Picture one: Working from behind. "This picture is taken from: Helping Children Who Are Blind, Family and community support for children with vision problems", (2004) Published by The Hesperian Foundation, Berkeley, California, USA.



Work from behind your child

When you are showing your child how to do a new activity, like feeding or dressing himself, it may be easier for him to understand your movements if you are behind him. Sometimes it works well to put your hands over his. But be sure to ask him first if it is okay.

Picture 2: A Happy child with Down’s Syndrome

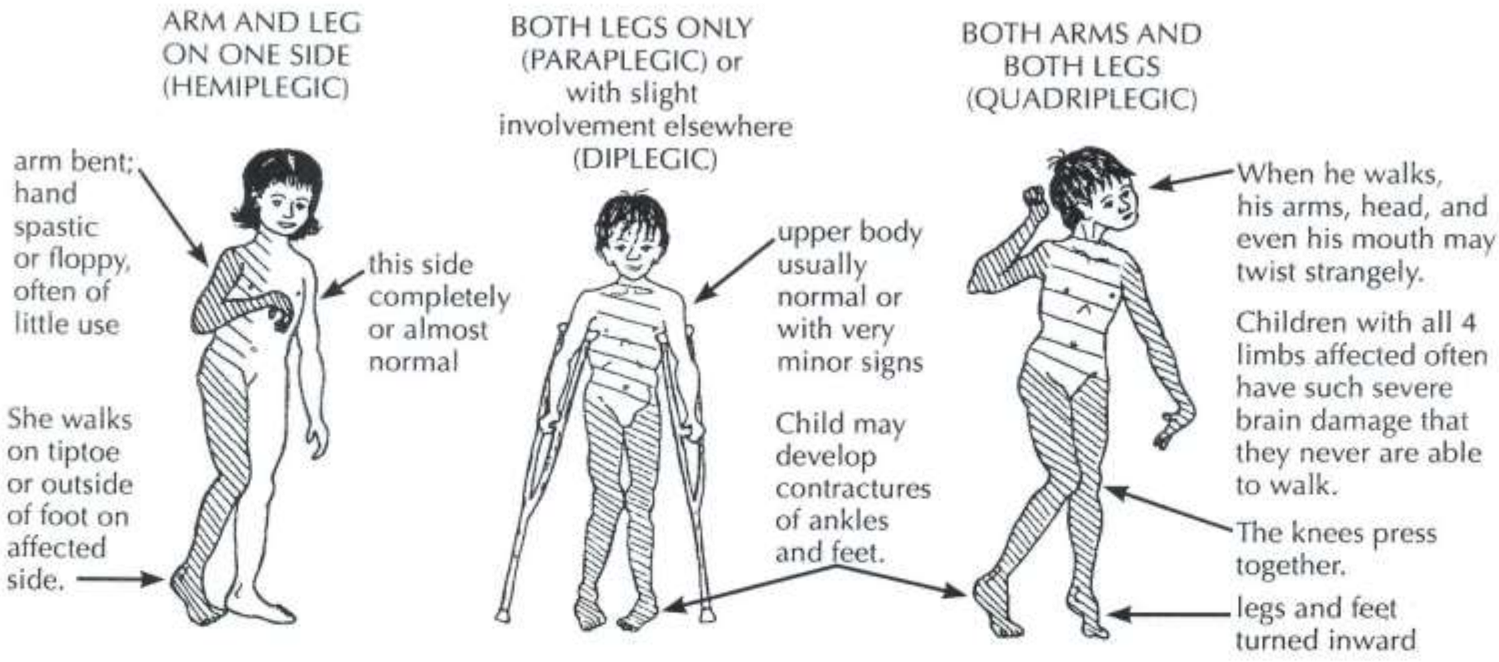
Down’s syndrome is a chromosomal disorder that causes intellectual disability and other health problems. But with good support, most children with Down’s syndrome can lead a happy, independent life.

http://www.parenting.com/gallery/a-special-joy-19-babies-with-down-syndrome-1000022984

Picture 3: Parts of the body affected by cerebral palsy. The following picture is taken from: "Disabled Village Children, A guide for community health workers, rehabilitation workers, and families (2nd edition)" (2009) Published by the Hesperian Foundation, USA.

Parts of the body affected

DEPENDING ON WHICH LIMBS ARE INVOLVED, THERE ARE 3 TYPICAL PATTERNS:



ARM AND LEG ON ONE SIDE (HEMIPLEGIC)

arm bent; hand spastic or floppy, often of little use

this side completely or almost normal

She walks on tiptoe or outside of foot on affected side.

BOTH LEGS ONLY (PARAPLEGIC) or with slight involvement elsewhere (DIPLEGIC)

upper body usually normal or with very minor signs

Child may develop contractures of ankles and feet.

BOTH ARMS AND BOTH LEGS (QUADRIPLEGIC)

When he walks, his arms, head, and even his mouth may twist strangely.

Children with all 4 limbs affected often have such severe brain damage that they never are able to walk.

The knees press together.

legs and feet turned inward

Although most cerebral palsy children fit one or another of these patterns, check also for minor problems in other parts of the body.

Picture 4: Club-foot before and after treatment by strapping

Left, Note the weight-bearing surface of the foot is on the side and top of the foot in this child with bilateral (two) clubfeet. **Right**, Note the deep crease on the bottom of the middle of the foot, which is one sign of clubfoot.

This is a picture of a patient <u>after</u> cast correction of a left-sided clubfoot deformity. Note that the calf is smaller on the left side, but the child basically looks “normal” and can function the same as any other child.

(http://orthoinfo.aaos.org/topic.cfm?topic=a00296)

ANNEX FOUR: SIGN LANGUAGE ALPHABET