

# They All Have Dreams

Community Based Rehabilitation for Children with Disabilities



Save the Children  
Norway-Ethiopia Program



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# **They All Have Dreams**

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## **Community Based Rehabilitation for Children with Disabilities:**

*Good Practices and Lessons from Save the Children Norway Ethiopia Programme Intervention*



## *From the Country Director*

Save the Children Norway – Ethiopia (SCN-E) is happy to share its experiences in working with and for children with disabilities in North Gondar Zone of the Amhara Regional State, Ethiopia. It is estimated that over 2.5 million children in Ethiopia are living with disabilities. It is also estimated that less than 1% of children with special needs access primary education. The main causes of disability among children in Ethiopia are preventable causes like poor nutrition, lack of pre-natal and neonatal health care, and harmful traditional practices.

Children with disabilities face social and familial rejection, and many are kept hidden at home, exposed to different forms of abuse, neglect and discrimination, and have limited access to social services due to lack of awareness and prejudice associated with spiritual and cultural beliefs among the society. Many of them are denied their right to education by families and the public in general. The inaccessibility of schools and lack of facilities are also prohibitive, in turn critically impede their capacity to succeed in education and other socio-economic activities.

Cognizant of the aforementioned problems for children with disabilities, SCN-E initiated an innovative project on Community Based Rehabilitation for children with disabilities, partnering with a government university - Gondar University Faculty of Medicine & Health Science, and a local non-governmental organization called Handicap National. The program is intended to support the protection of the children from all forms of abuse, improve their access to rehabilitation services by making optimum use of local resources, and promote inclusive education to allow them access into formal schools. The program adopts a multi-sectoral strategy to address the broader issues affecting the children.

SCN-E has documented the experience of the project at different levels and would like to share this with you. It is hoped that the document will initiate discussion and inspire other organisations to invest in improving the lives of children with disabilities in Ethiopia and elsewhere. It is our belief that partnering with both Gondar University and Handicap National has contributed to community ownership and sustainable impact. It has been possible to reach more children and families due to the partnership strategy.

SCN-E gratefully acknowledges the contribution of all the children and families who have shared their life experiences in this documentation. Additional thanks go to the partner organizations and staff members of Gondar University - Faculty of Medicine and Handicap National for the commitment and collaborative efforts throughout the implementation of the program. Lastly, SCN-E sincerely appreciates the government stakeholders and the target communities for their support and response to the call to protect and provide rehabilitation services to children with disabilities. I sincerely thank them for the contribution they have made in this document.

Lois Mushonga  
Country Director  
Save the Children Norway- Ethiopia

## Acronyms

<b>ACPF</b>	<b>African Child Policy Forum</b>
<b>CBR</b>	<b>Community Based Rehabilitation</b>
<b>CWDs</b>	<b>Children with Disabilities</b>
<b>FDRE</b>	<b>Federal Democratic Republic of Ethiopia</b>
<b>MOE</b>	<b>Ministry of Education</b>
<b>SCNE</b>	<b>Save the Children Norway - Ethiopia Programme</b>
<b>WHO</b>	<b>World Health Organization</b>



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## Key Facts about Children With Disabilities

- ◆ Nearly 15% of the world's population lives with a disability. Childhood disabilities (0–14 years), is estimated to be 95 million (5.1%) children, of whom 13 million (0.7%) have “severe disability” (WHO & the World Bank, 2011)
- ◆ It is estimated that over 2.5 million children in Ethiopia are living with disabilities (National Plan of Action for Children, 2003 – 2010 and beyond).
- ◆ Of the 15 million school age population of Ethiopia, 1.5 to 3 million have special needs. It is also estimated that less than 1% of children with special needs have access primary education (Ministry of Education, 2005)
- ◆ Children with disabilities (CWDs) have a 1.7% greater risk of being victim of violence than non-disabled children and girls with disabilities are more vulnerable (UNICEF as cited in ACPF, 2011)
- ◆ 5 – 20% of working children suffer injuries or illness that permanently affect or disable them e.g. loss of limbs, hearing, sight and burns (ILO 2006)
- ◆ The main causes of disability among children in Ethiopia are preventable causes like poor nutrition, lack of prenatal and neonatal health care, and harmful traditional practices (ACPF, 2011).

## About the Document:

The intention of this booklet is to document and share the good practices and results that the project has achieved at different levels with improved outcomes on the lives of the individual child with disability, families, the community, and institutions. Case studies and Key informant interviews were employed to document the good practices. CWDs and their families who have got different support through the project intervention, community leaders, children, government offices and other stakeholders have participated in the documentation process.



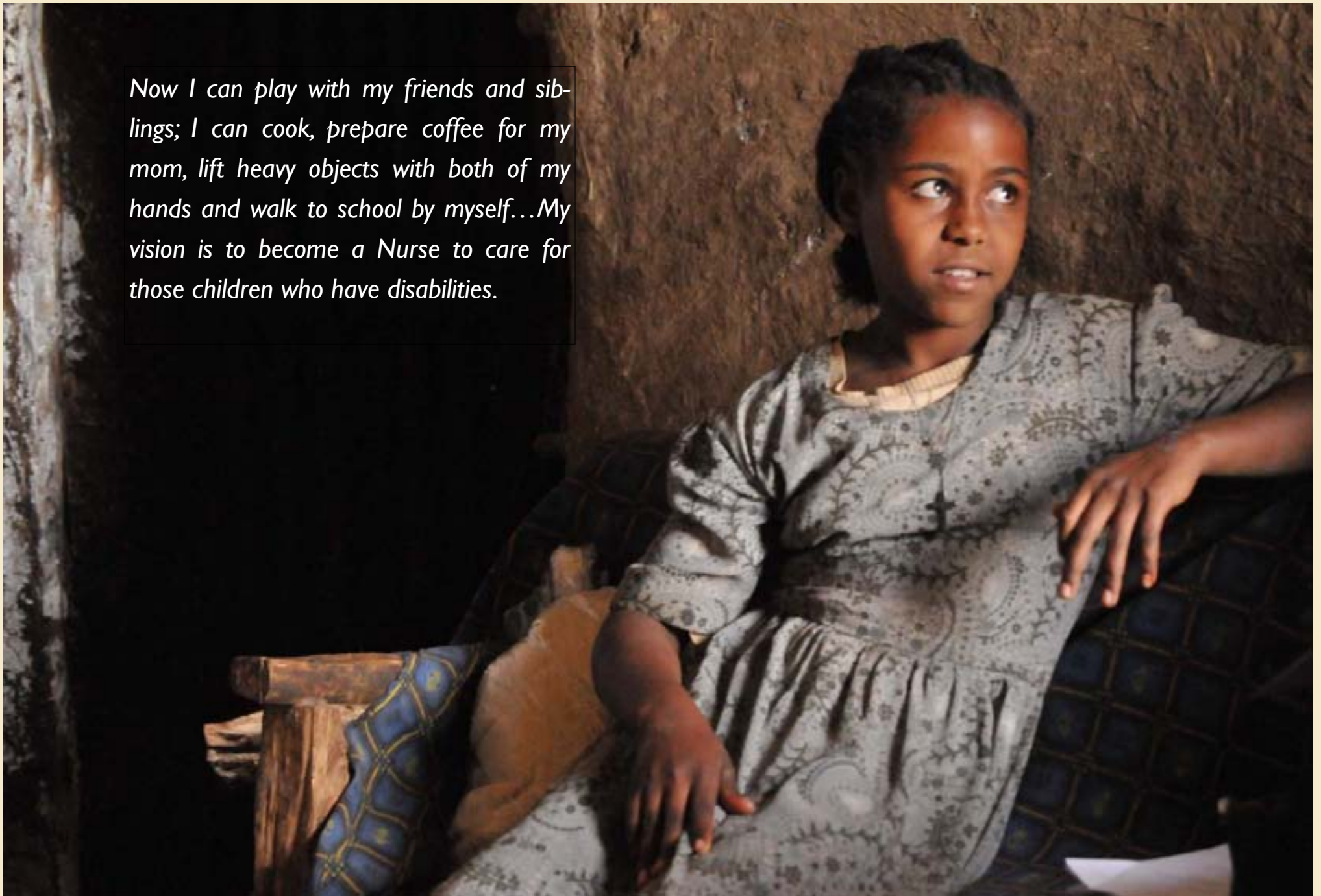
For the 12 year old girl, Workitu Tadesse, life took turn to a direction she never expected at her age. She was pushed by a horse and injured her leg which led to the development of gangrene that left one of her legs amputated. The change was not easy both for her and her family. She stayed at home for a year isolated from others, unable to do things she used to – going to school, playing with friends and looking after herself.

*“I felt so scared and was worried that I might die” says Workitu  
“I used to tell my friends ‘you are lucky because you can go to school and have a future, but I will die soon and be forgotten ...”*

After what she explains as a near death experience, Workitu was introduced to the CBR intervention in Chilga District, Aykel Kebele. She got back to her school after receiving home-based care, counseling, and medical support.

She clearly remembers the days she got her walking aid (Crutch) and artificial leg after having treatment at Gulele Orthopedic Centre in Addis Ababa and Gondar Hospital. Returning to school using the crutch was a frightening experience to the 2<sup>nd</sup> grader, *“When I pass the door and entered the classroom everyone was surprised, scared and stared at me. At that time I felt so embarrassed...”*

*Now I can play with my friends and siblings; I can cook, prepare coffee for my mom, lift heavy objects with both of my hands and walk to school by myself...My vision is to become a Nurse to care for those children who have disabilities.*



# Changing Misconceptions, Attitudes and Practices

Addressing the awareness gaps in the community is one of the CBR programme interventions

## Prior perception about disability

- It is a curse
- It is a punishment from God for parental or family sin
- A return for betraying people,
- An accident happened by the power of evil sprit
- A wind devil “Yenefas ganen”
- Failing to perform feasts to evil spirit

## “Stereotypical expressions”

“Puzzled/confused/mystified” for the child with vision and hearing disability

“Crippled” for mobility problem

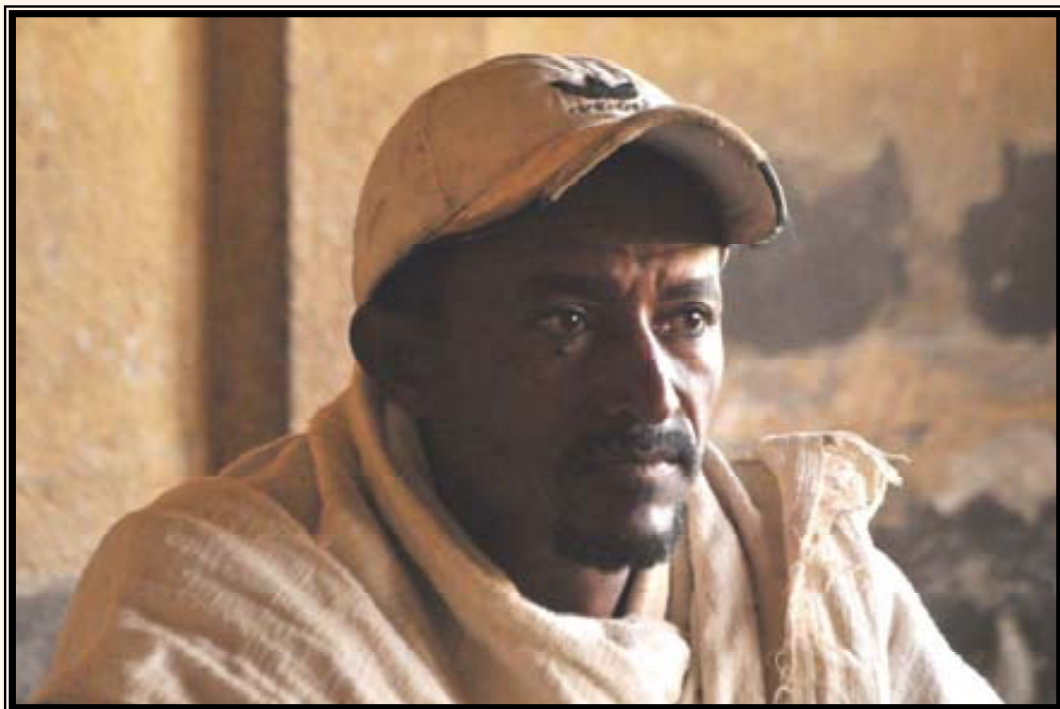
“Possessed by evil spirit” for mental illness.....

## Coping mechanisms

- Spiritual remedy
- Witch craft
- Traditional physio-therapist
- Ritual practices like breaking eggs, washing body with herbs
- Preparing feast to ‘evil spirit’
- Alienating the child with disability

For breaking through such misconceptions and practices and achieve changes, the programme used various strategies including:

- ♦ Community conversations and dialogue using existing social communication systems
- ♦ Collaborating with community members including religion leaders, the elderly and influential others, using them as change agents
- ♦ Organizing community members as CBR groups to respond for the protection of children with disabilities
- ♦ Having field workers from target communities
- ♦ Working with and strengthening coordination among key government sectors including the health, education, women, children and Youth affairs offices and schools
- ♦ Engaging children in project activities through child-led groups



I can testify the changes I observed in the community. Today, we know how to prevent disability and care for CWDs. We take all precautions when addressing the needs of persons with disabilities.  
(Community member)

I never thought that I would see changes on my grandchild and I was very suspicious when the field worker told me about existing supports for her. But from time to time I learnt a lot. Now I advise parents of CWDs in my community on how and where to get support for their children.





I used to believe that my child's problem was caused by evil spirit . People in my neighbourhood used to wish for me that God would take his life. But now everyone is happy with my child's progress and very supportive through the process.

## Using Existing Social Communication systems



Once in every two weeks neighbours from twenty to thirty people meet together to enjoy coffee and discuss about the causes and prevention mechanisms of disabilities among children and the protection of CWD.

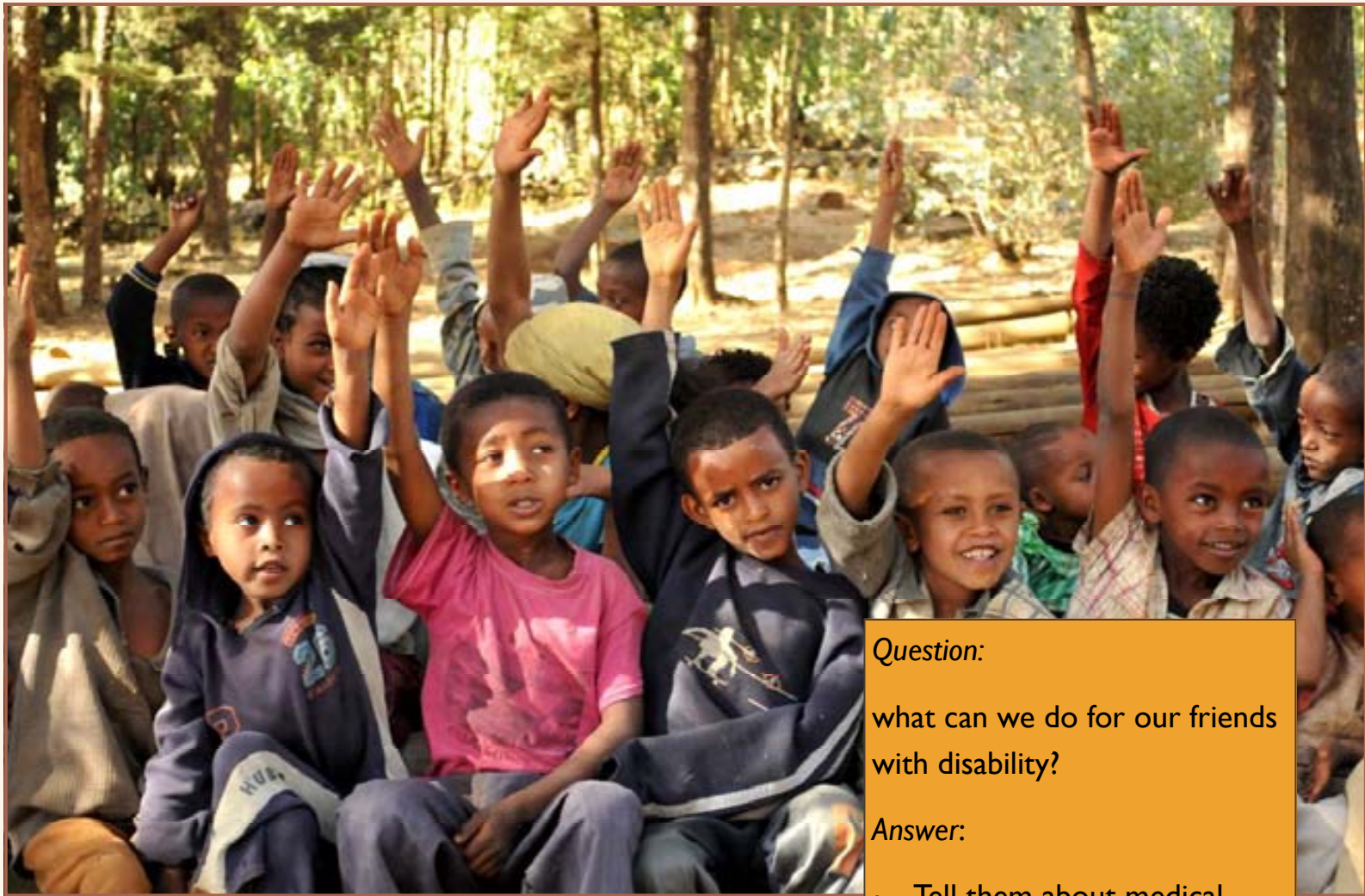
**Coffee ceremony** is a traditional practice whereby neighbours invite each other to their houses to maintain their good relationship and care while drinking coffee. It is also a time to discuss various social issues, resolve disagreements and propose solutions for matters that affect their wellbeing.

CBR programme uses coffee ceremony and other traditional communication systems as a strategy to bring to the forefront issues of disabilities among children and address different misconceptions, wrong attitudes and practices related to disabilities among the local people. Annually, an estimated 50,000 community members have been reached with this approach. An estimated 40,000 households have been reached through radio education programs on disability prevention and care.



## Awareness Raising Targeting Children

There is a weekly participatory education program organized by field workers for younger children whose ages are below ten years. It is conducted at village level and participate both in and out of school children. The children learn about disabilities, its types, cause and prevention methods. They are also encouraged to share their newly acquired knowledge with their peers in their neighbours and schools.



*Question:*

what can we do for our friends with disability?

*Answer:*

- Tell them about medical treatment
- Assist them when they go to school,
- Play with them ...

## Using community members as a bridge

The strategy of using field workers and supportive committee, selected from community members, is one of the key steps in gaining the trust and ownership of the project by the community.



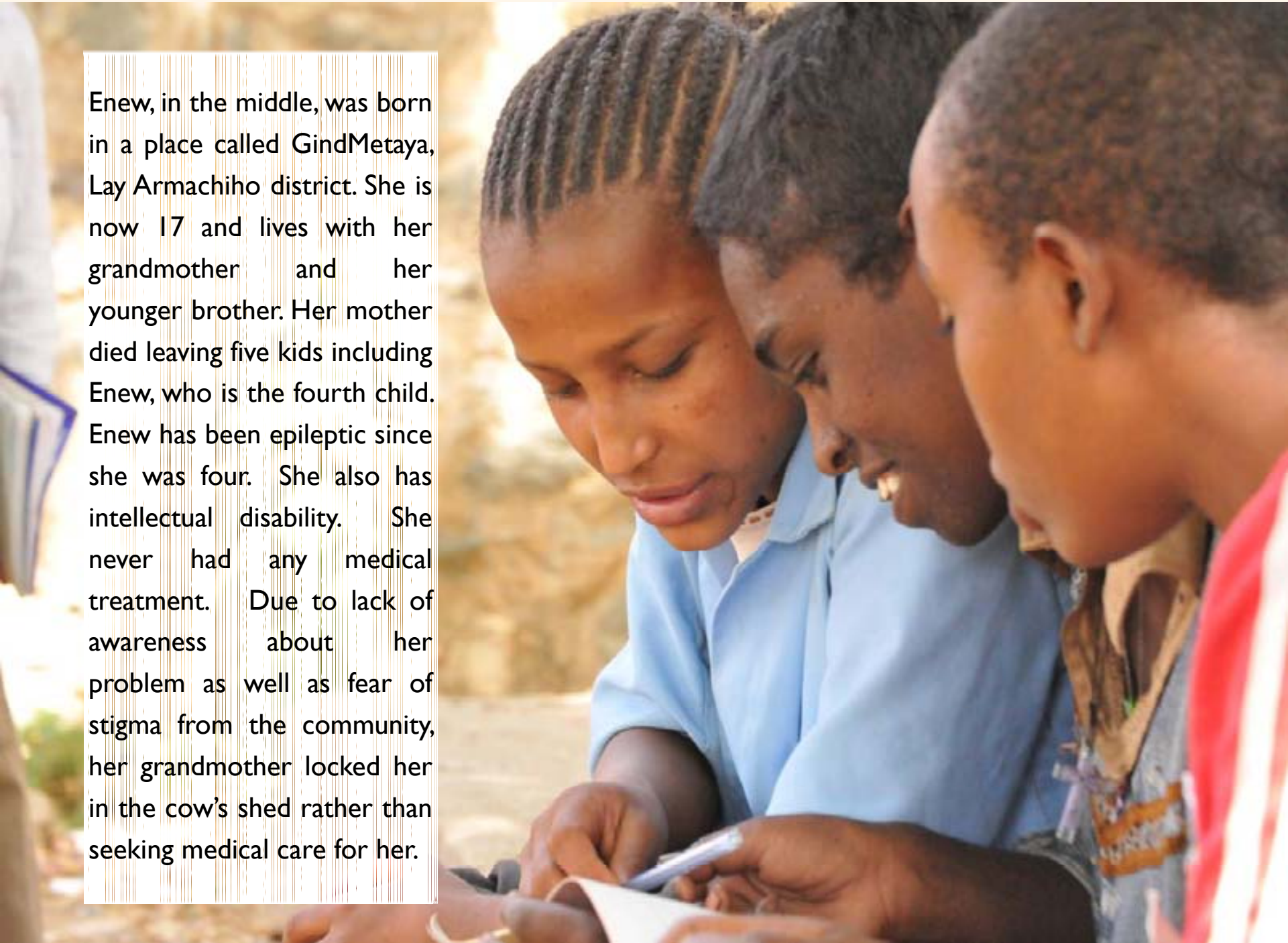
**Field Workers** who are community members trained by CBR program serve as a channel between the community and different level service providers for CWDs. They play a major role in the identification and rehabilitation of CWDs. Through their community education programs, regular house-to-house visits and parental education, and referrals for support, they ensure that CWDs get appropriate care and access to services.



**House-to-house visit** constitutes the day to day duties of CBR field workers. Given the inaccessible situation of the intervention areas in terms of transportation and topography, and over occupation of families on their day to day activities, the house to house visit is found to be effective strategy for delivering the support to the children and their families.

Sign language training, physiotherapy treatment, training on self-care and social skills, and counselling services are carried out during home visits. Field workers educate and enhance relationship within the family depending on the specific needs of families. Their interventions have led to improved inclusion of CWDs and their families in the wider community.

## From cowshed to school

A photograph showing three young girls in school uniforms. The girl in the middle is looking down at a book or paper held by the girl on the right. The girl on the left is also looking down. They appear to be in a classroom or library setting.

Enew, in the middle, was born in a place called GindMetaya, Lay Armachiho district. She is now 17 and lives with her grandmother and her younger brother. Her mother died leaving five kids including Enew, who is the fourth child. Enew has been epileptic since she was four. She also has intellectual disability. She never had any medical treatment. Due to lack of awareness about her problem as well as fear of stigma from the community, her grandmother locked her in the cow's shed rather than seeking medical care for her.

Enew's life continued locked up behind the cow's shed for about eight years. She was deprived of her rights to go to school, playing with peers, having family care and support and social interactions. She neither saw a sun light nor interacted with others which made her scared to be around other people.



*“It was very big embarrassment to raise her,” said the grandmother. “She did not know how to urinate and defecate, so it was uneasy to dispose her wastes and clean her. To clean her, we used to wait until it is dusk and cover her face so others would not see her. No one was willing to come into my house and drink the local beer ‘Tela’ which I used to earn my living from.*”

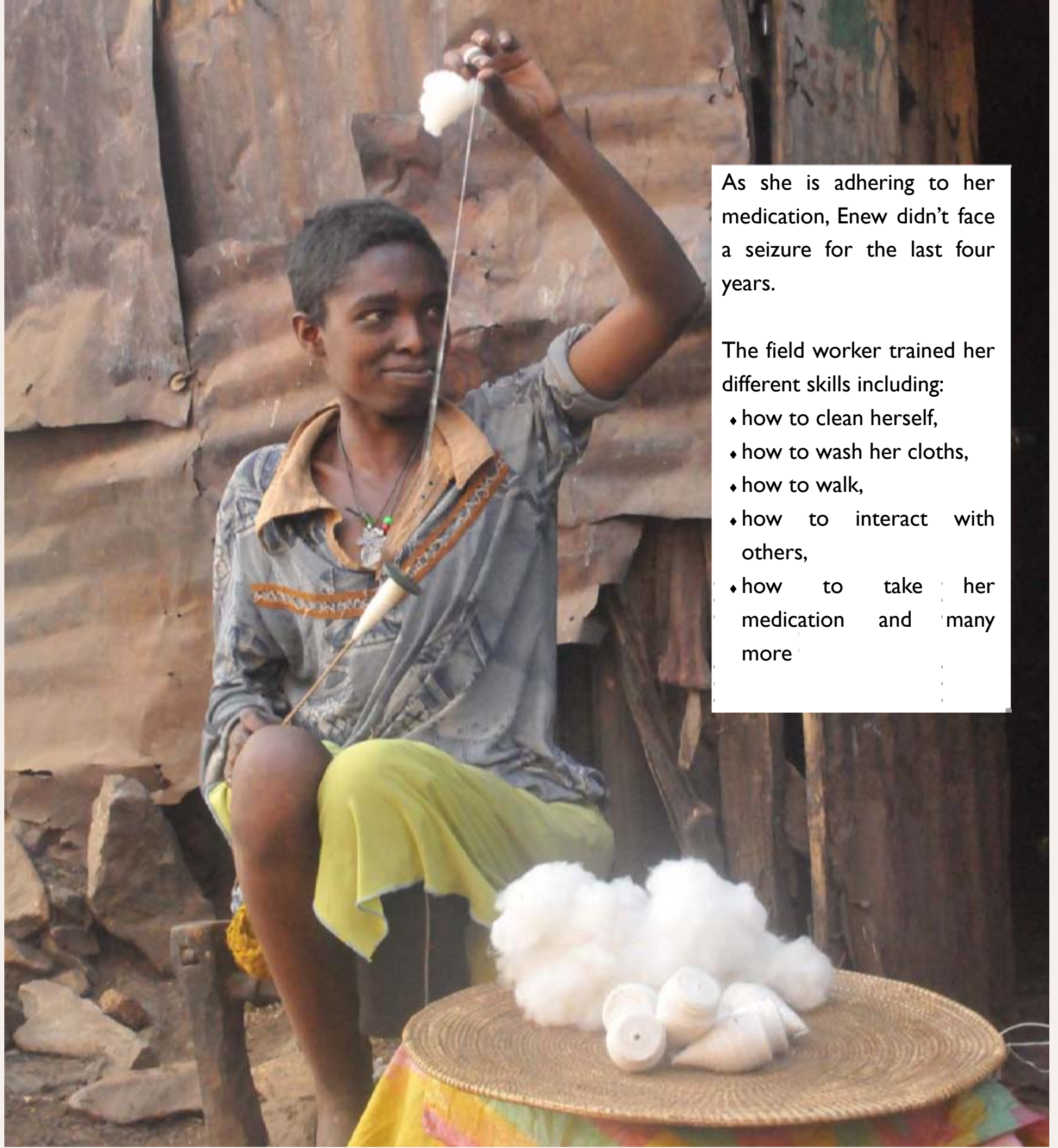
Though she was very suspicious at the beginning when approached by one of the fieldworkers of the CBR program, Enew’s grandmother is now an advocate for rights of CWDs in her community. She now strongly believes that the community awareness is the key to save so many children who are discriminated and hidden due to wrong beliefs.

*The CBR field worker comes regularly to support Enew every other week. Now I have got a lot of education from the CBR on how to take care of my grandchild, the need to continue medication and improving her skills. I have been in many meetings and shared my knowledge to those people in the same situation. I now advise people to get services and I also participate in community discussion through coffee ceremony programs.*

*... I regret my previous thoughts to give Enew poison because I believed her sickness is a kind that doesn’t take her life... But now I miss her even when she goes to school. She is very neat and keeps herself clean, and she cares for me; she is the one who takes care of me when I fall sick.*



Enew is now attending her education through inclusive education program. She interacts well and enjoys being with other children of her age



As she is adhering to her medication, Enew didn't face a seizure for the last four years.

The field worker trained her different skills including:

- ◆ how to clean herself,
- ◆ how to wash her cloths,
- ◆ how to walk,
- ◆ how to interact with others,
- ◆ how to take her medication and many more

## Community Participation and Response

**Community Supportive Committees** consist of religion leaders, the elderly, and parents of children with disabilities, schools and representatives from local government sector offices. They are initiating community led responses for the protection and rehabilitation of CWDs. The members of the committee have received training on the concepts of CBR and other issues related to disabilities among children. They teach the public in religious gatherings and other community meetings, and visit families of CWDs and render advices. They also identify and refer CWDs to the CBR office in their village, schools, health centres and other services.

### Early Identification and Intervention

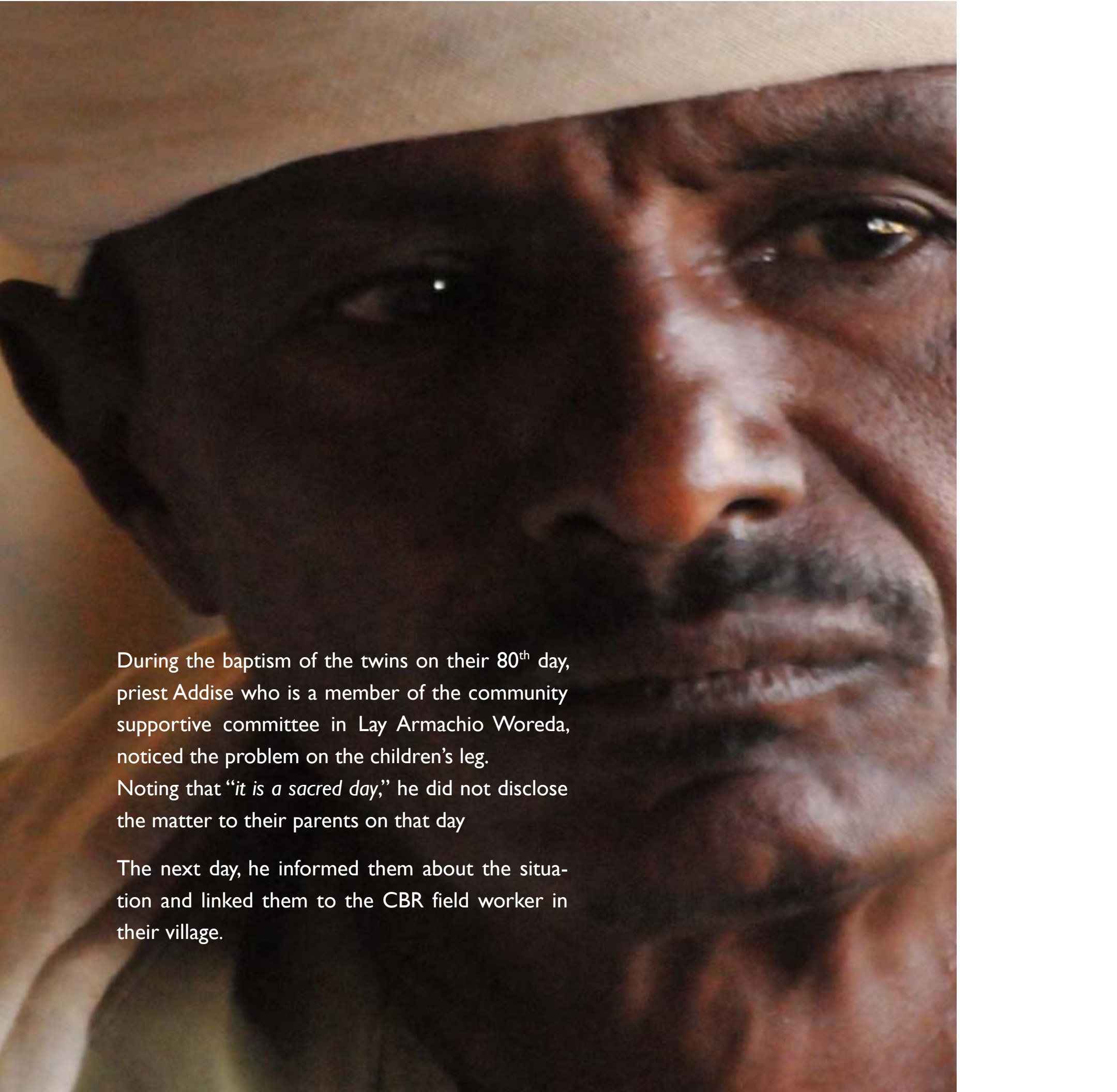
Early identification and intervention is one of the major aspects in enabling CWDs grow up to become productive and independent individuals. It supports their physical, social and cognitive development at early stage. It also minimizes cost and stress to which the children and their families are potentially exposed to.

The work with community supportive committees made early identification of CWDs possible and facilitated for early intervention.



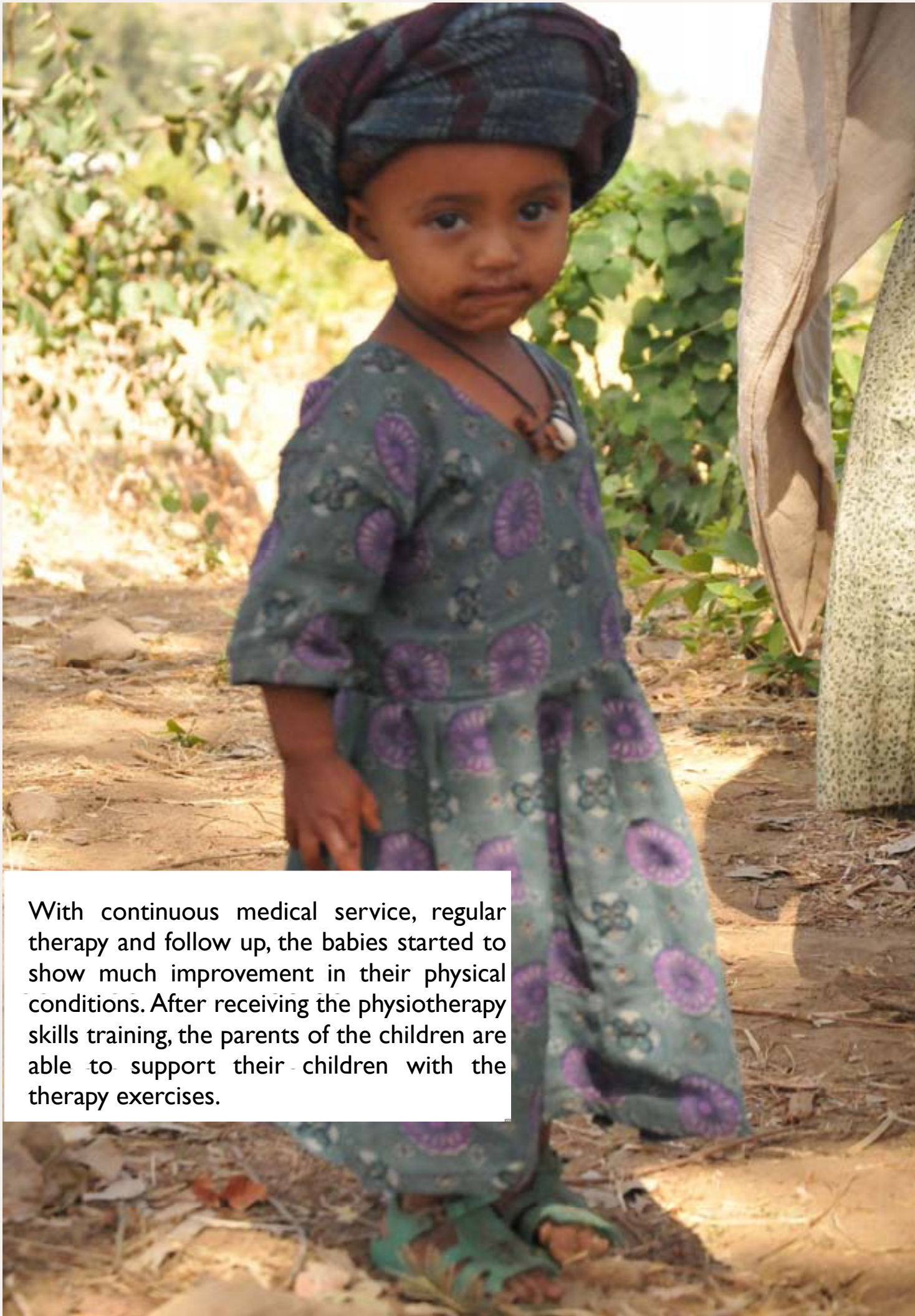
Ato Zewede and W/rt Zeweditu live in Lay Armachiho Woreda. They have two years old twin daughters named Zemenay and Emebet. The twins got club foot since birth. When the parents noticed the case, they both were shocked and felt embarrassed. They tried to hide the babies from neighbors and relatives.





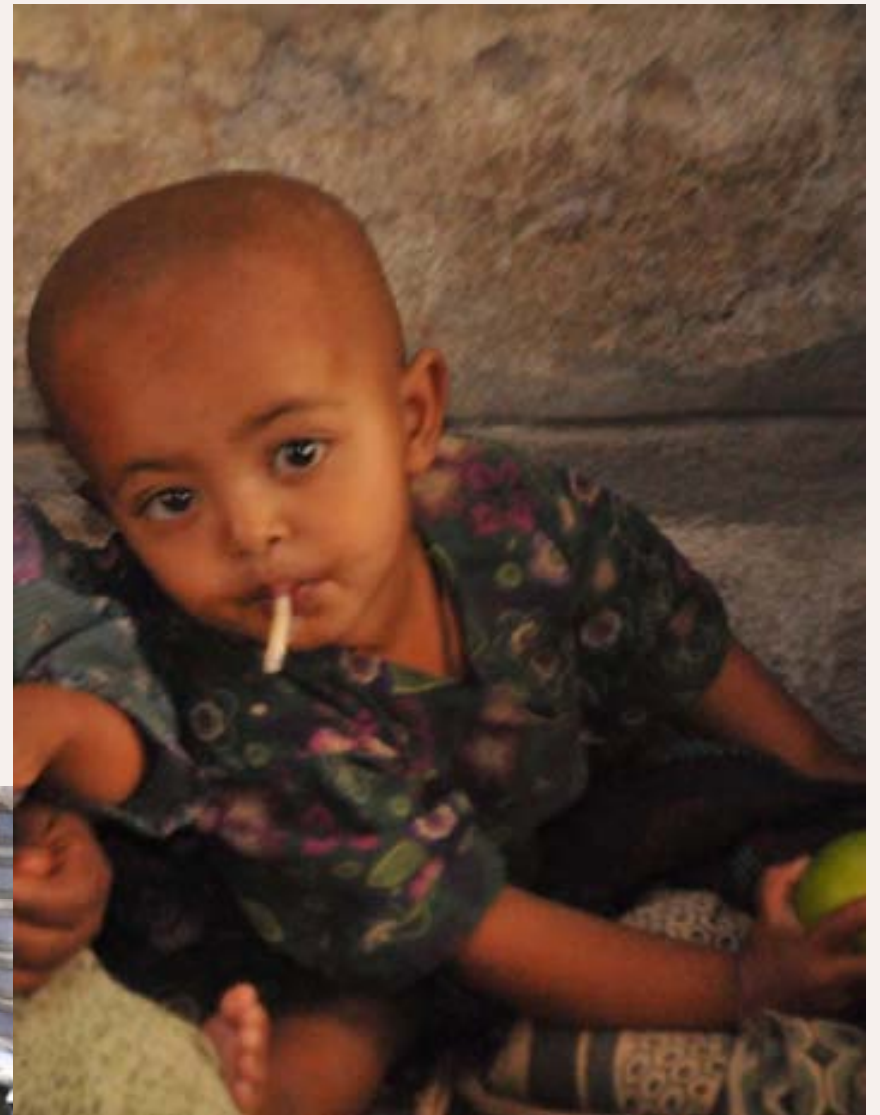
During the baptism of the twins on their 80<sup>th</sup> day, priest Addise who is a member of the community supportive committee in Lay Armachio Woreda, noticed the problem on the children's leg. Noting that "*it is a sacred day*," he did not disclose the matter to their parents on that day

The next day, he informed them about the situation and linked them to the CBR field worker in their village.



With continuous medical service, regular therapy and follow up, the babies started to show much improvement in their physical conditions. After receiving the physiotherapy skills training, the parents of the children are able to support their children with the therapy exercises.

Zemenay is now completely cured and is able to walk very well while Emebet is almost there.

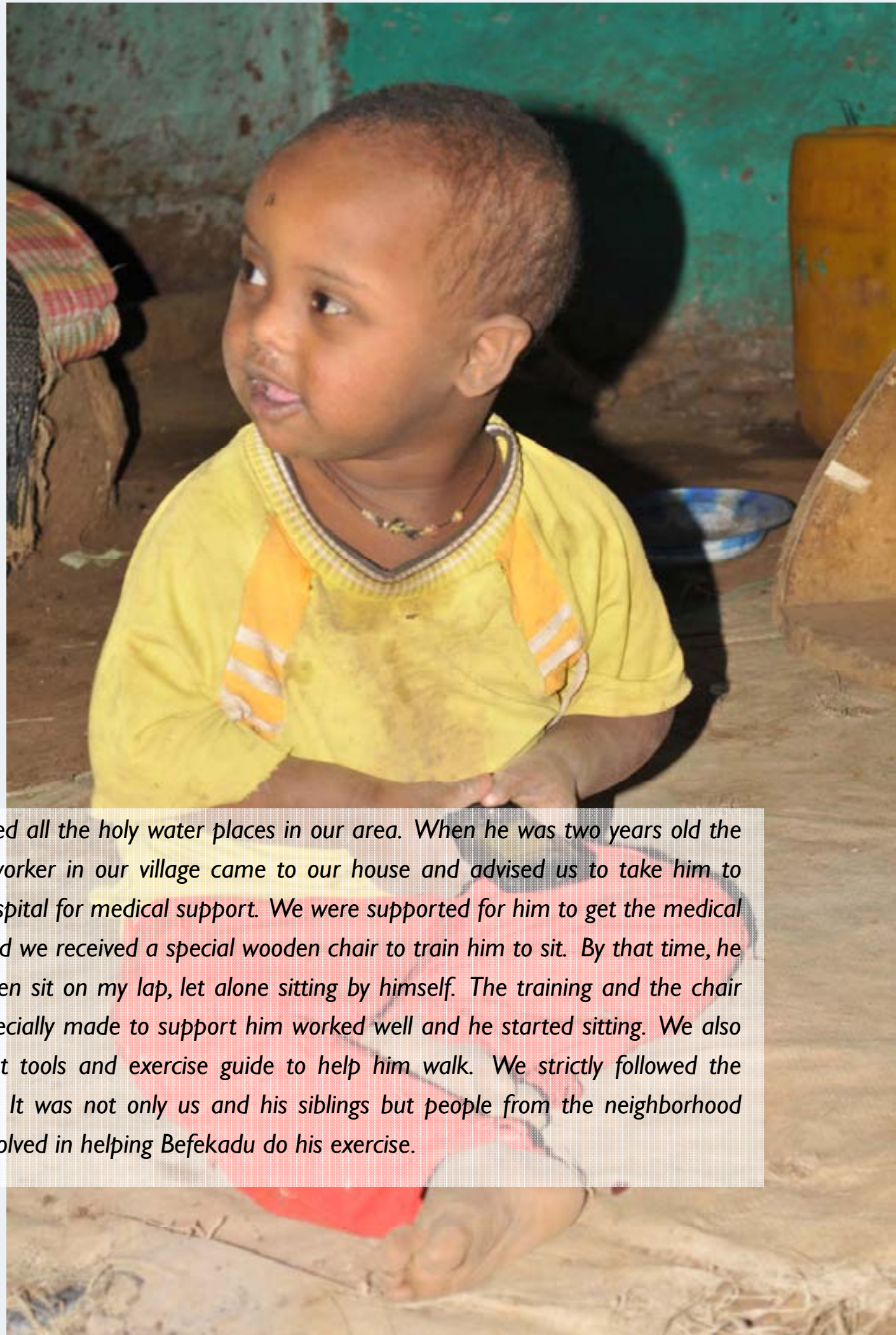


## Skill Transfer and Family Empowerment

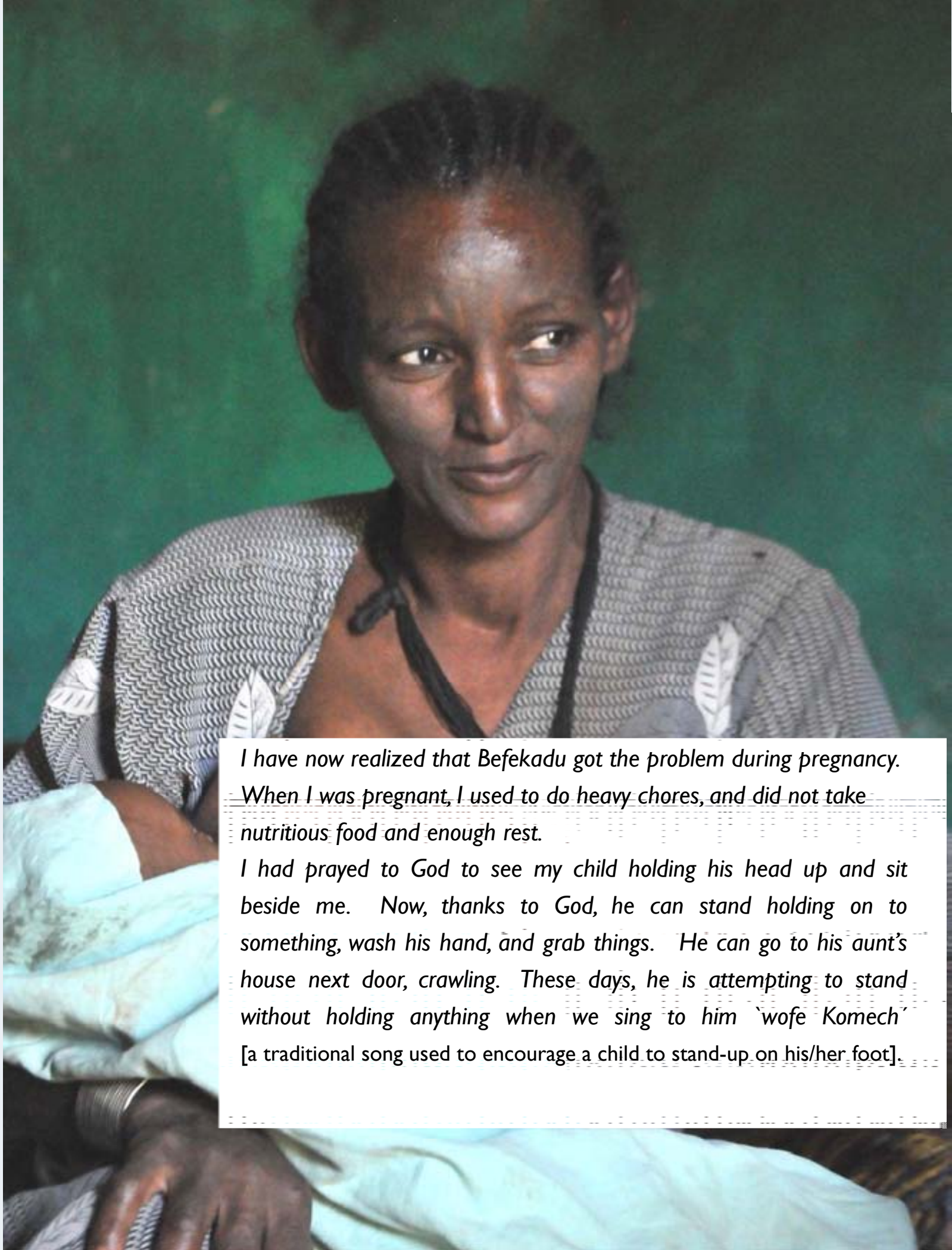
Regular home visits are made to families of CWDs to teach them basic skills to care for their children such as sign languages and different techniques of physiotherapy.



*I am Worke and he is my husband Dagne. This is our son Befkadu. Befkadu is 5 years old and our fifth child out of the six children we have. When Befkadu was born, we realized that he looked different since he did not cry as infants do. We sensed that there was some problem with him. Even when he was about two years old, he was not able to sit, move, or hold things with his hand. He used to stay in one place unless someone moved him. And the worst thing, he never cried as babies even for food...*



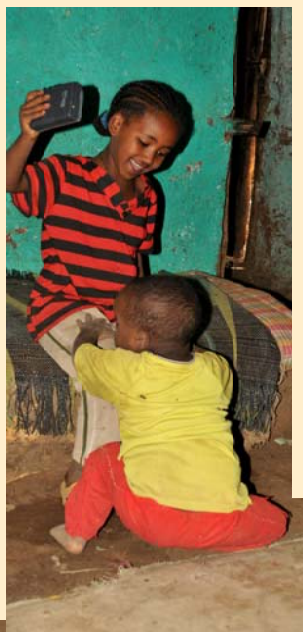
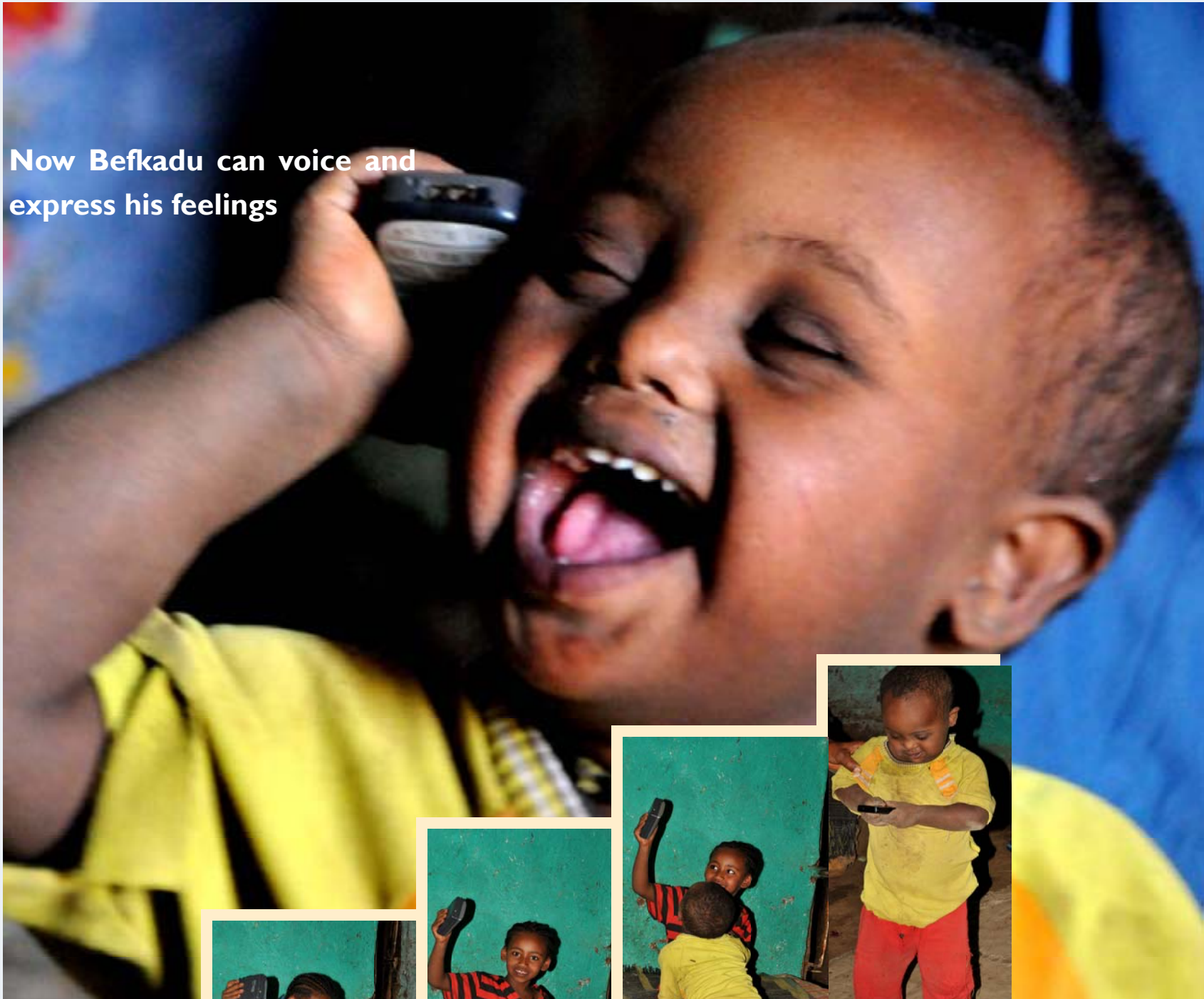
*... We visited all the holy water places in our area. When he was two years old the CBR field worker in our village came to our house and advised us to take him to Gondar Hospital for medical support. We were supported for him to get the medical checkup and we received a special wooden chair to train him to sit. By that time, he wouldn't even sit on my lap, let alone sitting by himself. The training and the chair which is specially made to support him worked well and he started sitting. We also got different tools and exercise guide to help him walk. We strictly followed the instruction. It was not only us and his siblings but people from the neighborhood also are involved in helping Befekadu do his exercise.*



*I have now realized that Befekadu got the problem during pregnancy. When I was pregnant, I used to do heavy chores, and did not take nutritious food and enough rest.*

*I had prayed to God to see my child holding his head up and sit beside me. Now, thanks to God, he can stand holding on to something, wash his hand, and grab things. He can go to his aunt's house next door, crawling. These days, he is attempting to stand without holding anything when we sing to him 'wofe Komech' [a traditional song used to encourage a child to stand-up on his/her foot].*

Now Befkadu can voice and express his feelings



## Promoting Family Wellbeing for the Benefit of CWD

The CBR programme has response measures to the different needs of a child with disability and her/his family. Supports including referrals for health care, psychological, livelihood, educational and other psychosocial supports are provided. Moreover, the programme addresses the social environment of CWDs focusing on the family, neighbours, schools, churches, etc. to support the wellbeing and social inclusion of the individual child and family.

Bearing the psychological challenges of caring for CWD, social discrimination, extra effort for care giving, economic problem associated with child's medical cost, absenteeism from work and quitting jobs are among the major factors that burden families of CWDs. Considering these facts, the CBR intervention promotes family wellbeing and empowerment by focusing on integrated services. That includes parental economic empowerment, skill training and support for emotional and behavioral adaptation to the child's condition.





Endalkachew was five years old when he failed on a playground and developed muscle contraction. Travelling a long distance to get traditional physiotherapy was tiresome for his parents and older sister.

The financial burden on the family had been so immense that the resources spent in search of a solution for their son had resulted in a conflict between his parents. It was a challenge for the family, in particular to the mother, to care for him and her other four children.

Moreover, Endalkachew's aggressive behavior made the care giving process very challenging. He used to quarrel with his siblings and neighbors, lacked interest in his school and other activities of his age. It was at this time that CBR intervention in Chilga Woreda (district) facilitated different support to Endalkachew and his family. That includes physiotherapy, home-based follow-up, counseling and livelihood supports.



Endalkachew's mother is now involved in income generating activities after getting livelihood training and financial support. The small shop she opened at her house has helped her earn income to support her children. Now she joyfully witnesses the difference that the support she received from the CBR brought to her and her family's life.

*“Before it was difficult for me to send my children to school and provide for their other basic needs. It got worse when my husband left me. Now I have managed to fulfill my children's need. I even constructed two additional living rooms and got enough space for the tea shop. Before it was difficult for my children to study or to eat since the ‘tea shop’ and the resident were together,. Now we have our family privacy”*



# Safe and Supportive School Environment

## **Inclusion Matters**

Combined efforts were made and necessary support has been given by the project to create enabling environment for CWDs to access formal education to schools . Religious leaders, elders in the community and field health extension workers play important role in creating awareness and identifying and referring CWDs to schools. Moreover, CWDs from destitute families are exempted from annual school registration fee in an effort to motivate parents of CWDs to send their children to school. Consequently, increased number of CWDs are enrolled in formal schools in the intervention areas of Chilga and Lay Armachiho Weredas (Districts).

## School Child-Led Clubs

There are child-led disability clubs in primary schools in the intervention areas. These clubs promote inclusion and supportive social environment for CWDs in and outside schools. Students with disabilities and with no disability as well as teachers are members of the clubs. Every two weeks, the disability clubs organize awareness rising events using dramas, role play, short poems and songs, in the schools and community at times of holydays, social and religious gatherings and other events.



The children in the child-led clubs are also involved in different activities to promote the physical school environment for CWDs. Leveling pavements and construction/ renovation of toilets in a way they be suitable for CWDs are among their activities. They also promote the participation and social inclusion of students with disabilities in different school activities.

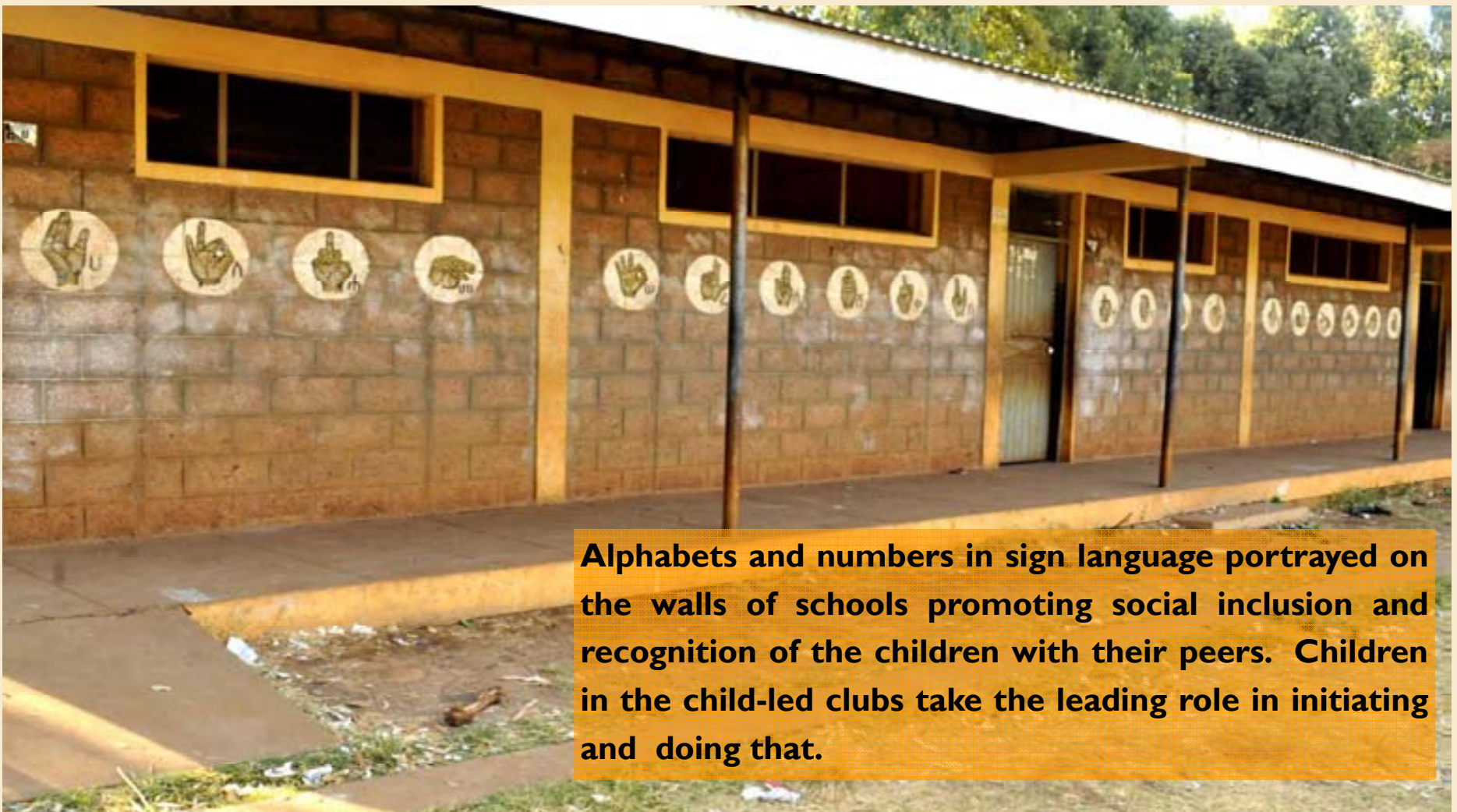




Gude (left), Alemtsehaye (middle) and Abeba (right) are grade 3 students in Selam Fere primary school

Gude, Alemtsehay, and Abeba are siblings who have hearing impairment since birth. They are 16, 12, and 14 years old respectively. They live with their parents in a village called Abek Yelesh, an hour walking distance from Selam Fere Primary School, Lay Armachio District.

It was not an easy task to convince the parents who used to believe that children with hearing impairment are incapable of learning. Besides, the parents were afraid of the stigma within their community and kept the children at home hidden from the public. After several efforts of convincing the parents, now the children are attending their third grade education in Selam Fere Primary School. The school disability clubs have played a significant role in supporting the social inclusion of the children with their peers.



**Alphabets and numbers in sign language portrayed on the walls of schools promoting social inclusion and recognition of the children with their peers. Children in the child-led clubs take the leading role in initiating and doing that.**





In Limat Ber Primary school, there is a model Montessori class where children with mental retardation and those with learning disabilities get special assistance in an inclusive manner with other children. The Montessori class has special teaching aid materials with different forms, colors, size and types. It facilitates active and practical learning. The school has assigned a teacher to the Montessori class who has got training in special needs education.

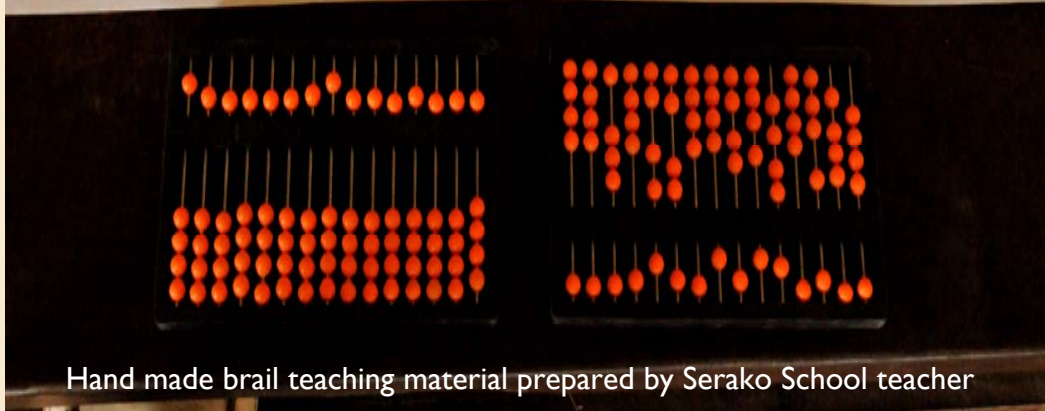


Children learning through touching, playing, assembling materials, grouping etc





School teachers have taken short term courses on special needs education, inclusive education, sign language and Braille at different times.

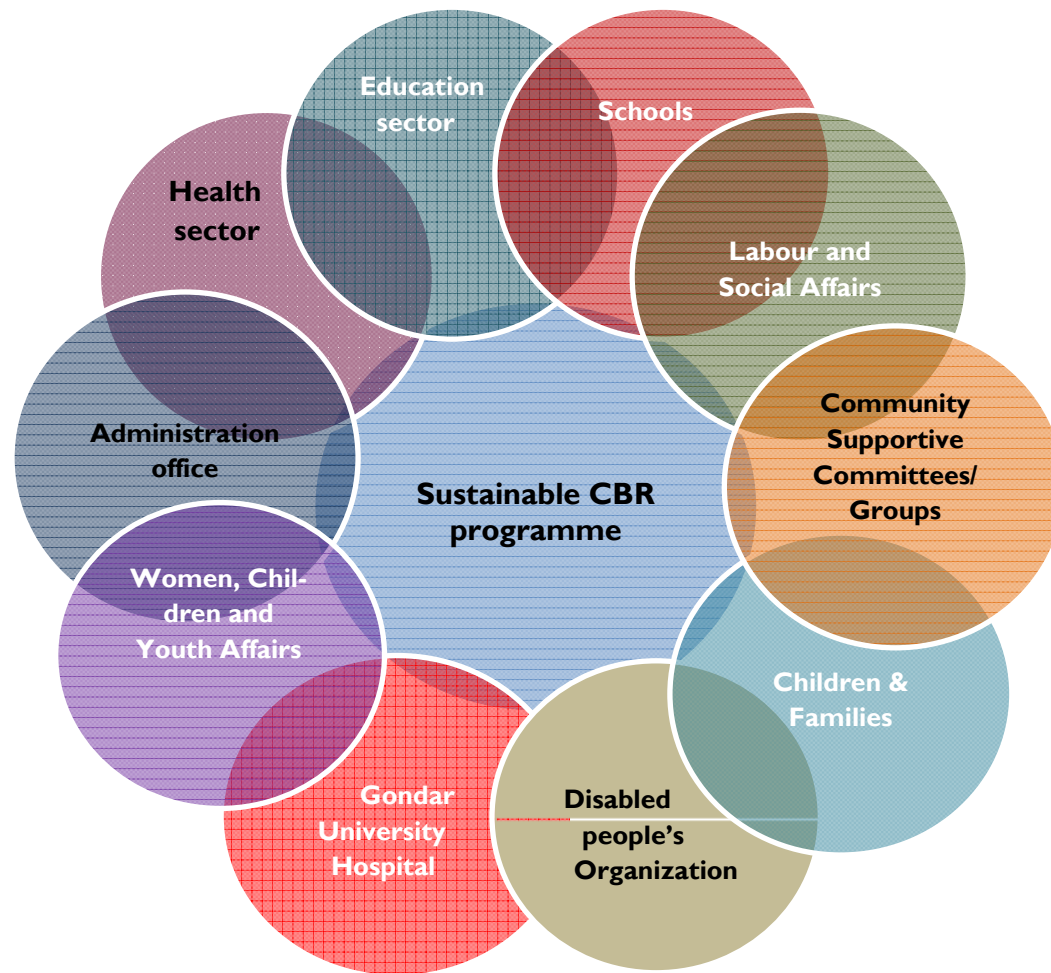


Hand made brail teaching material prepared by Serako School teacher

The gates to classrooms of all schools in the intervention areas are made physically accessible for students who have mobility difficulties.



# Bringing All Together



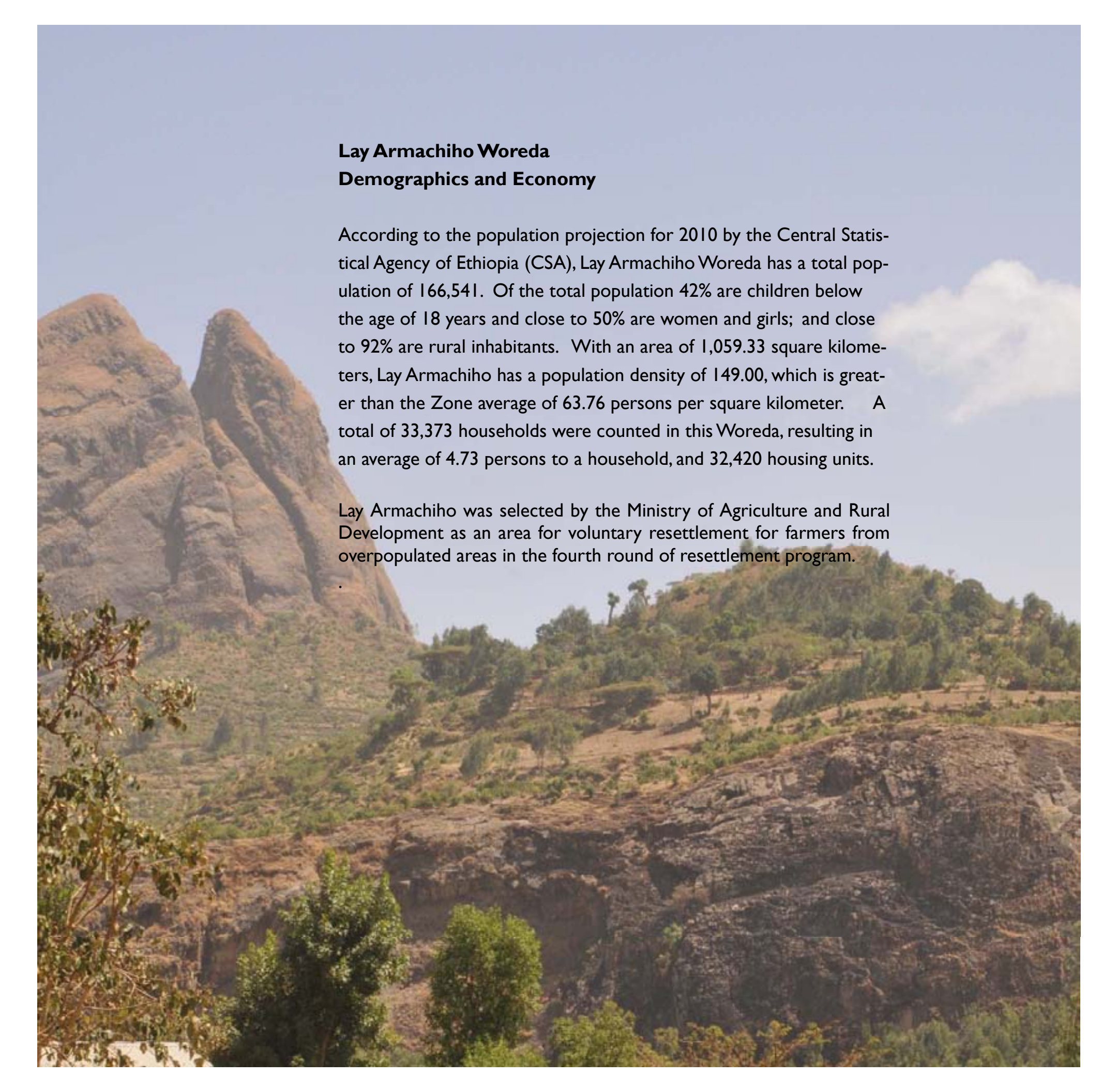
The prevention and response efforts for CWDs necessitates the close collaboration of different actors from the community to higher government structures. The CBR programme supports the efforts of bringing all different stakeholders together and this contributed to ensuring ownership and sustainability of the programme intervention in the target areas. This approach also resulted in an improved coordination and referral linkages among the different sectors.

- ◆ Improved coordination and working linkages have been established among government offices at Kebele and Woreda levels resulting in an improved access to services for CWDs, including medical, school, housing, and other psychosocial supports. The health, local administration, education, Women, Children and Youth Affairs, Labour and Social Affairs, Gondar University Hospital, Schools and CBOs are among the key sectors involved.
- ◆ There is a smooth referral linkages established with Health Centers and the Gondar University Hospital for medical supports. Furthermore, Health Extension Workers in each village are engaged in awareness creation, identification, counseling, and referrals of CWDs.
- ◆ Schools have been playing a vital role in promoting access to school for CWDs, supporting the inclusive education through trained teachers and disability clubs. All schools in the intervention areas are inclusive where CWDs are admitted and have been pursuing their education.
- ◆ Community Committees have been highly engaged in the CBR interventions supporting the public trust, engagement and ownership of the programme interventions
- ◆ CBR programme is incorporated in the curriculum of the Sociology Department of Gondar University, as one of the courses. Added to this, students in Gender Studies, Psychology, Sociology and other departments are involved in research activities through the programme. Students from Physiotherapy Department are involved providing outreach services for CWDs and their care providers through field placement of students
- ◆ CBR programme is now incorporated in the Strategic Plan of the university being revised, with long-term plans and advocacy work to initiate CBR training center within the university premise



## Lessons learned

- ◆ Targeting both the CWDs and their family was crucial to respond for the rehabilitation and protection of the children. The skill transfers for care providers including parenting, physiotherapy, sign language, and livelihood support, and the counseling support both for the CWDs and their whole family were fundamental for the sustainable rehabilitation of the children.
- ◆ The role and commitment of different Government Sectors is crucial and is dependent on one another when dealing with a wide range of issues of children with disabilities and their families. Supporting the working linkage and coordinated efforts of the different sectors was an effective approach to act in a systematized and strategic manner in dealing with issues of CWDs and in promoting their protection and access to services.
- ◆ Strengthening the referral linkages among the different sectors was effective in facilitating holistic responses to the children and enabling mandated sectors respond to the rights of the children
- ◆ Building the capacity of the local community groups and linking them with different government sectors has proven to be an effective approach in strengthening community response for the protection and rehabilitation of CWDs.
- ◆ Promoting child participation through child led clubs has shown encouraging results in promoting the inclusion of the children in formal schools and in the communities at large. Children have been active in identifying and reporting “hidden” children with disabilities in their neighbourhoods and in conducting awareness raising activities in their respective communities and schools.

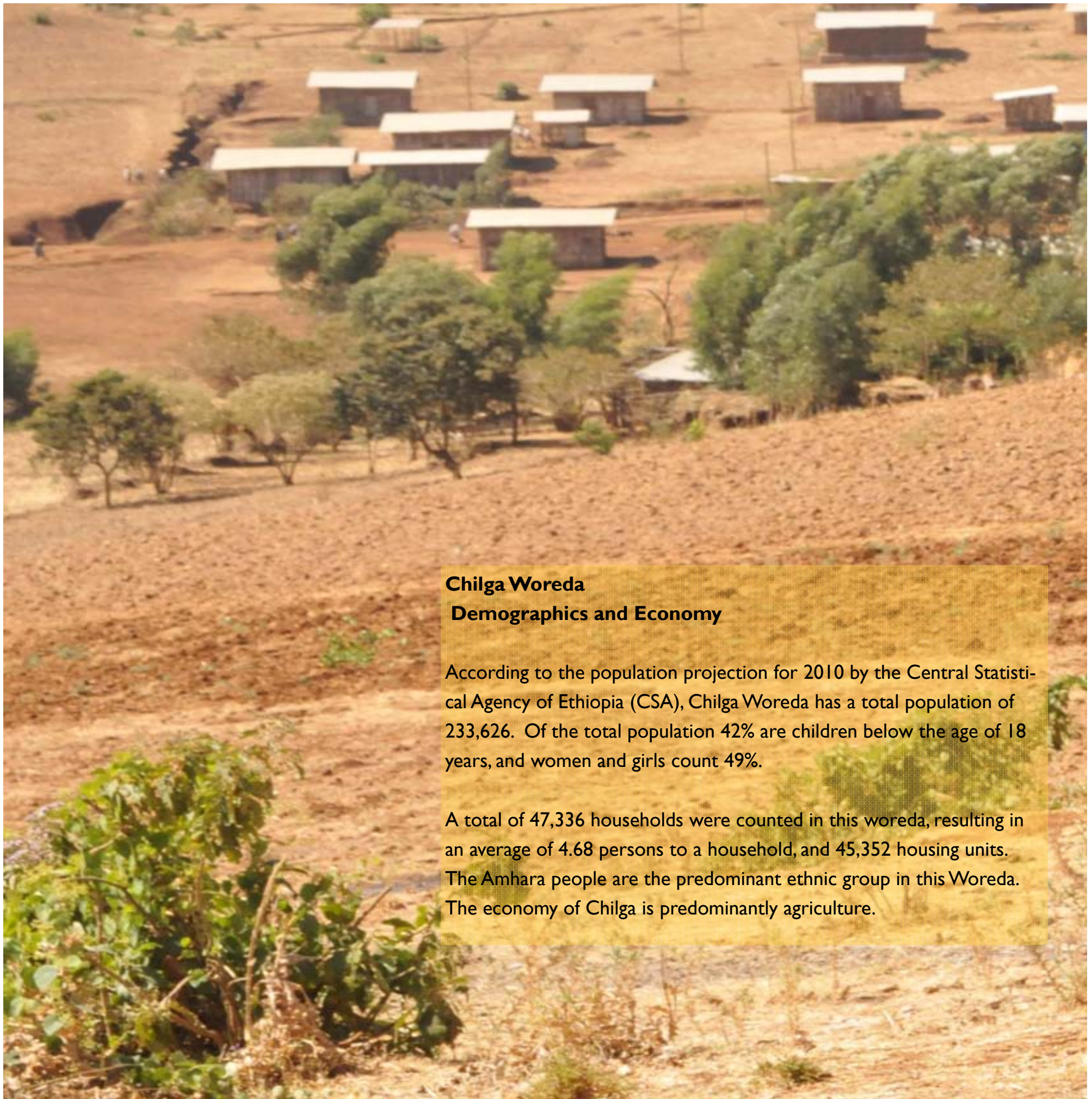


## **Lay Armachiho Woreda**

### **Demographics and Economy**

According to the population projection for 2010 by the Central Statistical Agency of Ethiopia (CSA), Lay Armachiho Woreda has a total population of 166,541. Of the total population 42% are children below the age of 18 years and close to 50% are women and girls; and close to 92% are rural inhabitants. With an area of 1,059.33 square kilometers, Lay Armachiho has a population density of 149.00, which is greater than the Zone average of 63.76 persons per square kilometer. A total of 33,373 households were counted in this Woreda, resulting in an average of 4.73 persons to a household, and 32,420 housing units.

Lay Armachiho was selected by the Ministry of Agriculture and Rural Development as an area for voluntary resettlement for farmers from overpopulated areas in the fourth round of resettlement program.



### **Chilga Woreda Demographics and Economy**

According to the population projection for 2010 by the Central Statistical Agency of Ethiopia (CSA), Chilga Woreda has a total population of 233,626. Of the total population 42% are children below the age of 18 years, and women and girls count 49%.

A total of 47,336 households were counted in this woreda, resulting in an average of 4.68 persons to a household, and 45,352 housing units. The Amhara people are the predominant ethnic group in this Woreda. The economy of Chilga is predominantly agriculture.

## About Us

Save the Children is the world's leading independent organization for children. Save the children Norway has been working in Ethiopia since 1969.

Our vision is a world in which every child attains the right to survival, protection, development and participation.

Our mission is to inspire breakthroughs in the way the world treats children, and to achieve immediate and lasting change in their lives.

Our values are accountability, ambition, collaboration, creativity and integrity.



Save the Children  
Norway-Ethiopia Programme







Results of skills training