

# **Children with disabilities in Ethiopia: The hidden reality**



The African Child  
Policy Forum



# **Children with disabilities in Ethiopia: The hidden reality**

## The African Child Policy Forum (ACPF)

ACPF is an independent, pan-African institution of policy research and dialogue on the African child.

ACPF was established with the conviction that putting children first on the public agenda is fundamental for the realisation of their rights and wellbeing and for bringing about lasting social and economic progress in Africa.

ACPF's work is rights based, inspired by universal values and informed by global experiences and knowledge. Its work is guided by the UN Convention on the Rights of the Child, the African Charter on the Rights and Welfare of the Child, and other relevant regional and international human rights instruments. ACPF aims to specifically contribute to improved knowledge on children in Africa; monitor and report progress; identify policy options; provide a platform for dialogue; collaborate with governments, inter-governmental organisations and civil society in the development and implementation of effective pro-child policies and programmes and also promote a common voice for children in and out of Africa.



### The African Child Policy Forum (ACPF)

P. O. Box 1179

Addis Ababa, Ethiopia

Telephone: +251 11 662 8192/96/97/99

Fax: +251 11 662 8200

E-mail: [info@africanchildforum.org](mailto:info@africanchildforum.org)

Website: [www.africanchildforum.org](http://www.africanchildforum.org)

[www.africanchild.info](http://www.africanchild.info)

© 2011 ACPF

### Suggested Citation:

ACPF (2011). *Children with disabilities in Ethiopia: The hidden reality*. Addis Ababa: The African Child Policy Forum.



## Acknowledgments

We wish to extend our appreciation to the Ethiopian Centre for Disability and Development (ECDD) for coordinating this project in Ethiopia.

Sincere thanks also go to the technical team: Martha Alemayehu, Nigussie Dejene, Yehualashet Mekonnen, David Mugawe, Islay Mactaggart, Retta Getachew, Bob Ransom and Nafisa Baboo for their significant contribution to the success of this project at various stages including the design of the study, the preparation of research tools and report writing.

Our sincere gratitude also goes to our funder, Save the Children Sweden (ECAf) for recognising the importance of this study and making it possible.

ACPF is also grateful to the large network of disabled people's organisations, non governmental organisations and relevant government bodies, which were all instrumental in identifying respondents.

Further appreciation also goes to the international experts who commented on and validated the research instruments, namely Dr Phillipa Lei (world Vision UK), Arne Henning (SINTEF), Gerison Lansdown (CRIN) and Dr Nora Groce (LCDRC).

Finally, we wish to express our deepest gratitude to the disabled children and their care givers who responded to the questionnaires. Through their willingness to participate and share their situations with us, we were able to document their reality for the benefit of a much wider group.



## Acronyms

<b>ACPF</b>	The African Child Policy Forum
<b>BoLSA</b>	(Regional) Bureau for Labour and Social Affairs
<b>CBM</b>	Christoffel Blindenmission
<b>CBR</b>	Community-Based Rehabilitation
<b>CBRN</b>	Community Based Rehabilitation Network (of Ethiopia)
<b>CRIN</b>	Child Rights Information Network
<b>CSA</b>	Central Statistics Authority (of Ethiopia)
<b>DPO</b>	Disabled Persons' Organization
<b>ECDD</b>	Ethiopian Center for Disability and Development
<b>ENAB</b>	Ethiopian National Association of the Blind
<b>ENAD</b>	Ethiopian National Association of the Deaf
<b>ENAID</b>	Ethiopian National Association for Intellectual Disability
<b>ENAPH</b>	Ethiopian National Association of the Physically Handicapped
<b>ESDP III</b>	Third (National) Education Sector Development Plan
<b>FDRE</b>	Federal Democratic Republic of Ethiopia
<b>FENAPD</b>	Federation of Ethiopian National Associations of Persons with Disability
<b>HSDP</b>	Health Sector Development Programme
<b>LCDRC</b>	Leonard Cheshire Disability Resource Centres
<b>MoLSA</b>	Ministry of Labour and Social Affairs
<b>NGO</b>	Non-Governmental Organization
<b>PANE</b>	Poverty Action Network in Ethiopia
<b>PASDEP</b>	(National) Plan for Accelerated and Sustainable Development to End Poverty
<b>SNE</b>	Special Needs Education
<b>TVET</b>	Technical and Vocational Educational Training
<b>UNCRPD</b>	United Nations Convention on the Rights of Persons with Disabilities
<b>UNDP</b>	United Nations Development Programme



# Contents

<b>Acknowledgments</b>	<b>i</b>
<b>Acronyms</b>	<b>ii</b>
<b>Preface</b>	<b>iii</b>
<b>Executive summary</b>	<b>iv</b>
<b>1. Introduction and study background</b>	<b>1</b>
<b>2. Study context</b>	<b>3</b>
2.1 Ethiopia and how it functions	3
2.2 Overview of disability in Ethiopia	4
2.3 Legislation and policies that guard the rights of children and adults with disabilities in Ethiopia	7
2.3.1 <i>Summary of major legislation</i>	7
2.3.2 <i>Expansion on constitutional rights, department mandates and policies</i>	8
2.4 Inclusivity of children with disabilities in mainstream national policies	9
2.5 The role played by non-governmental organisations	11
<b>3. Research methodology</b>	<b>13</b>
3.1 Preliminary activities and research design	13
3.2 Quantitative data collection	13
3.3 Qualitative data collection	14
3.4 The sample	15
3.5 Study limitations	16
<b>4. Results of the survey</b>	<b>19</b>
4.1 Profile of childhood disability	19
4.1.1 <i>Distribution</i>	19
4.1.2 <i>Cause and onset of disability</i>	21
4.1.3 <i>Limitations on functioning</i>	23
4.2 Household and family dynamics	25
4.2.1 <i>Family dynamics</i>	25
4.2.2 <i>Dwelling</i>	26
4.3 Access to social services and support	28
4.3.1 <i>Attitude towards children with disabilities</i>	28
4.3.2 <i>Happiness of disabled children</i>	30
4.3.3 <i>Awareness of children's rights to access services and support</i>	32
4.3.4 <i>Access to education and learning support</i>	33
4.3.5 <i>Access to health care and wellbeing</i>	41
4.3.7 <i>Access to financial and emotional support</i>	47

4.4 Social integration	50
4.4.1 <i>Participation in family</i>	50
4.4.2 <i>Participation in community life</i>	54
<b>5. Commentary</b>	<b>57</b>
5.1 Education	57
5.2 Health care	57
5.3 Poverty and wellbeing	57
5.4 Family participation	58
5.5 Employment	58
5.6 Social barriers and community support	58
<b>6. Recommendations</b>	<b>61</b>
6.1 Education	61
6.2 Health care	62
6.3 Poverty and disability	63
6.4 Employment	63
6.5 Community support	64
6.6 Key advocacy messages	64
<b>7. Conclusion</b>	<b>67</b>
<b>Appendices</b>	<b>69</b>
Appendix 1: List of quotes by Research Participants	69
Appendix 2: A day in the life stories	71
<b>References</b>	<b>75</b>

## Figures

Figure 1: Map of Ethiopia	3
Figure 2: The link between disability and poverty	6

## Tables

Table 1: Summary of major legislation and policies that shape the provision of services for children with disabilities	7
Table 2: Mainstream national policies that refer to inclusivity of disabled children	9
Table 3: Breakdown by gender and disability type for returned child questionnaires	15
Table 4: Breakdown by child's gender and disability type for returned carer questionnaires	16
Table 5: Future professions: top five answers from child questionnaires	38
Table 6: Main income source for respondents' households	47

## Graphs

Graph 1: Religious profile of child respondents	19
Graph 2: Ethnic profile of child respondents	19
Graph 3: Age profile of child respondents	20
Graph 4: Birth registration of child respondents	20
Graph 5: Cause of disability, by disability type (carer questionnaire)	21
Graph 6: Age onset of disability, by cause and disability type	22
Graph 7: Ability of disabled children to carry out certain tasks and activities (carer questionnaire)	23
Graph 8: Assistive device needed by child respondents	24
Graph 9: Relationship of primary carers to the disabled child in their care	25
Graph 10: Where child respondents live	26
Graph 11: Adaptations to dwellings (by dwelling type)	27
Graph 12: Primary water source for households of child respondents	27
Graph 13: Carers' attitudes towards disability	30
Graph 14: Percentage of unhappy child respondents, by gender and disability type	31
Graph 15: Children's perception of future happiness	31
Graph 16: Awareness of child rights	32
Graph 17: School enrolment of child respondents, by gender and disability type	34
Graph 18: Number of child respondents who have had to repeat at least one grade in school, by gender and disability type	35
Graph 19: Homework and school support for child respondents (child questionnaire)	36

Graph 20: Interaction of child respondents with their peers and teachers in school	37
Graph 21: Carers' perception of their child's school	39
Graph 22: Child respondents' perceptions of school	39
Graph 23: Types of health service available to disabled children in their community (carer questionnaire)	41
Graph 24: Reasons disabled children do not use available known health services (carer questionnaire)	42
Graph 25: Health service providers [currently available to child respondents]	43
Graph 26: Improvements seen by carers after using healthcare services, by type (carer questionnaire)	44
Graph 27: Type of work done by child respondents who work for money, goods or favours, by gender	45
Graph 28: Working child respondents' perceptions of their work	46
Graph 29: Workplace conditions and experiences travelling to and from work (child questionnaire)	47
Graph 30: Financial impact of child's disability on the household (carer questionnaire)	48
Graph 31: Support received by carers in the last 12 months (carer questionnaire)	49
Graph 32: Chores undertaken by child respondents, by gender (child questionnaire)	50
Graph 33: Chores undertaken by child respondents, by disability type (child questionnaire)	51
Graph 34: Hours a day spent doing chores (child questionnaire)	52
Graph 35: Days a week spent on chores (child questionnaire)	52
Graph 36: Child respondents' perception of their chores	53
Graph 37: Disabled children's standing in the community and relationships with other community members	54
Graph 38: Favoured recreation activities	54

## Pictures

Picture 1: Henok prepares to sleep after an afternoon playing football with his friends	28
Picture 2: Adissu with his school friends	37
Picture 3: Adissu attaches his prosthetic leg	42
Picture 4: Getachew and his sister fetching water, one of his chores	51
Picture 5: Adissu helping prepare akenbalo, the family's only source of income	52

## Preface

Children with disabilities in Africa are among the most neglected groups in the policy domain as well as in the private sphere. The majority of these children face enormous economic, political, and social barriers that have an adverse impact on their physical, social and intellectual development and wellbeing. Many of them do not have access to the most basic needs such as health services and education, experience multiple deprivations even within their family and are invisible in national policy agenda.

The African Child Policy Forum (ACPF) believes that revealing the realities and drawing attention to the life situation of children with disabilities is the first step to lay the foundation for the establishment of sound policies, strategic plans and effective services and support to children with disabilities in Africa. It is within this context that the ACPF took the initiative to document the reality of children with disabilities and their families in Africa through in-depth studies aimed at generating evidence about their situation and by so doing it hopes to encourage greater national commitment to children with disabilities.

The multiple-country study is an effort to make the situation of children with disabilities more visible, so that parents, community leaders, policy makers, as well as child rights activists and their organisations, commit themselves to better protecting and promoting the rights of children with disabilities. The study seeks to analyse how cultural, social, physical and other societal barriers prevent children with disabilities from enjoying their constitutional rights to equality, freedom and human dignity. It also seeks to establish opportunities and practices that could be used to address these barriers to enhance disabled children's participation in society.

Children with disabilities in Ethiopia: The hidden reality is therefore part of a multiple-country study conducted by ACPF. We hope that this report serves its purpose and contributes towards guaranteeing children with disabilities to equal opportunities, treatment and full participation in Ethiopia. It is our greatest hope that this research supports the formulation and implementation of national policies, programmes and legislations that promote the full participation, equality and empowerment of children with disabilities in Ethiopia.

David Mugawe  
Executive Director



## Executive summary

*Children with disabilities in Ethiopia: The hidden reality* is part of a multiple-country study conducted by the African Child Policy Forum (ACPF). In Ethiopia, Senegal and Uganda, the study interviewed approximately 540 disabled children and their primary carers; while a desk review gathered information on the realities of disabled children in South Africa.

The study in Ethiopia was conducted in four of the country's most populous regions – Amhara; Oromia; Southern Nations, Nationalities and People's (SNNPR); and Tigray – as well as two chartered cities, Dire Dawa and the capital, Addis Ababa. The study identified children aged 9-17 with hearing, intellectual, physical, visual and multiple disabilities in both rural and urban settings; and conventional (household) and unconventional (in institutions or on the street) environments.

*“Disability does not mean inability. If our needs are met, we can be just as successful as our non-disabled peers. It is wrong to say that disabled children are unable to be independent”.*

### **Deaf boy, 15**

The research design included both qualitative and quantitative data collection methods, so as to document the complete situation faced by respondents. All respondents were fully informed of the research objectives and outputs, and all quantitative and qualitative interviewees were thoroughly

trained on appropriate, respectful and non-biased interview techniques.

Primary data analysis was conducted by SPSS (statistical package for the social sciences), and thematic analysis was conducted for the qualitative data. Relevant secondary data was thoroughly reviewed and analysed.

Anecdotally, disability proponents frequently refer to the situation of disabled children in Ethiopia as bleak. Children with disabilities are not seen in schools, and due to their consequent lack of access to skills and education, are not seen in gainful employment once they become adults. Moreover, they are often neglected or abused by their families, peers and communities, and excluded from many of their basic and legal rights that are enshrined in the 1994 constitution as well as international treaties – including the United Nations Convention on the Rights of the Child (UNCRC), and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) – to which Ethiopia is party.

The study findings show that, although enormous improvements are still needed to ensure the full and equal inclusion of disabled children in Ethiopian society, there have been positive moves forward in recent years in key areas – including education, stigma deterioration and community participation – towards improving their situation.

A surprisingly high number (76%) of the Ethiopian sample were enrolled in education. One possible explanation for this high figure could be the sampling method employed in this research. Snowball sampling was necessary as a consequence of the unavailability of disability prevalence data, but meant that children were identified primarily through non-governmental organisations (NGOs) and local government offices, increasing their likelihood of having access to basic services. National survey evidence suggests that the vast majority of children with disabilities are not in school, and anecdotal evidence suggests many do not have access to community-based rehabilitation (CBR) (CSA 2008). Unfortunately, due to the respondent identification process we had to use, this population was under-sampled.

However, even among those enrolled in inclusive and special schools, the ability to continue with their learning past a certain stage was problematical. This was for multiple reasons, including the facts that:

- many inclusive schools do not teach disabled children past Grade 5 (despite vocational training courses requiring a Grade 10 qualification);
- the vast majority of mainstream schools are physically inaccessible;
- a hugely inadequate number of teachers are being trained in special needs education (SNE);
- most schools lack the appropriate equipment – such as braille or audio materials and classroom assistants

– to facilitate inclusive learning.

These findings show that Ethiopia's SNE strategy must be reinforced, appropriately monitored and effectively evaluated and budgeted, to ensure that inclusive educational policy is a reality.

The lack of access to primary, rehabilitative and medical health services was an area of concern for many children in the study. A large number (38% of the total sample, and 60% of those with visual disabilities) had been disabled through illness. Of the carers who knew about health services that would be beneficial to their child, 69% used them. Of those who did not, 28% said they could not afford to do so. Furthermore, 55% found the health services they used had little or no impact on their child's health. Additionally, 14% of the sample had no access to a toilet. The links between poor hygiene/sanitation, inaccessibility and ineffectiveness of health care services and the onset of preventable disability is an area that needs further attention and appropriate policy design, to protect children from avoidable disability and effectively treat those in need.

Thirty-four per cent of the sample felt that they needed assistance from a device, or from a person and a device, to perform one or more of a series of activities. Most of these had access to the devices they needed, which must again be seen in the context of the snowball sampling via CBR programmes. Once using a device or receiving assistance from a person, 18% no longer had a problem, 66%

still had a problem, but found that it had improved, 15% said the problem had not improved and less than 1% felt the problem had got worse. Access to assistive devices, and carer education on providing assistance to disabled children is imperative, in order to improve functioning and independence over environmental factors.

The children who took part in the study were found to be relatively involved in their family and community activities, and significant number of children reported incidents of physical and verbal abuse from other children or adults. However, many felt obliged to take on employment or painful chores; many were excluded from certain situations; and there was multiple evidence of a lack of understanding among carers of the best ways to assist their disabled child. Seventeen per cent of the children worked either in or outside of the house for money, goods or favours; 68% of these were 15 years old or older, but 26% were 11-14 and 6% were 10 or under. Given the Ethiopian Labour Law forbidding employment of minors under the age of 14, these findings show that the government must ensure stricter adherence to employment laws to prevent the exploitation of disabled children and guarantee their participation in education rather than employment below a certain age.

Seventy-seven per cent of carers felt unable to afford the basic needs of their households, and few had access to any support in caring for the disabled child under their care. We therefore recommend further and sustained education, as well as emotional and

financial support for carers of disabled children.

Numerous NGOs working in different areas of Ethiopia shared many examples of good practice in improving the situation of disabled children. These are documented in the report; we recommend that they are highlighted and used to shape government policy for replication across the entire country.

An encouraging majority of children interviewed had high aspirations for the future and believed in their abilities to live full and independent lives – the onus is therefore on the state, communities and carers to give each disabled child the capacity to fulfil their aspirations on an equal basis with other children.

The following three key advocacy messages emerged from the study:

- Children with disabilities have a right to education, health care and equal opportunities. Their voices should be heard by, and communicated directly to, their peers, families and communities, in order to promote inclusion in all fields. A child-centric approach is imperative in combating exclusion, stigma and prejudice, and child ambassadors should be included in all discussions regarding disabled children in Ethiopia.
- Government, NGOs, communities and the private sector should work together to identify and learn from good practice in inclusive education, health care, work and employment opportunities. They should also raise awareness at community and family levels. All sectors should

develop inclusive policies that are based on good practice so they can replicate and implement successful initiatives across the country.

- Programmes and budgets for improving the situation of disabled children must be specific, realistic, structured, monitored and evaluated to ensure effective service delivery and the progressive implementation of disability-inclusive policies and practices. Task forces are needed in

both government and NGO sectors to ensure accountability of action and universal coverage.

*“Disability should not be seen as a disease. Disabled children can learn, play, work and perform just like other people without disability. All persons – those with disabilities and the rest of the community – should know this”.*

**Carer of a girl with an intellectual disability**

## 1. Introduction and study background

The African Policy Child Forum (ACPF) in partnership with The Ethiopian Centre for Disability and Development (ECDD) and with financial support from the Tides Foundation (USA), has completed a comprehensive study to document the life situation faced by Ethiopia's disabled children. The study is part of a wider ACPF project, which includes similar surveys in Senegal and Uganda, and a desk-based review in South Africa.

Knowledge about disability is not widespread in Ethiopia: few disabled children receive an education; many disabled adults are unemployed; and outdated historical beliefs about the cause and nature of disability are common. Furthermore, disability is frequently seen as a charity issue: there is minimal understanding of the *social* model of disability, which views impairment as an ordinary part of life, and disability as the result of society's lack of accommodation to – and discrimination against – disabled persons.

Persons with disabilities are defined in this study in accordance with Article 1 of the UNCRPD, ratified by Ethiopia in June 2010, which states that:

*“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others”.*

Understanding how disability is perceived in a specific culture is fundamental in the development of relevant and effective inclusionary programmes. With that in mind, the key objectives of this study were to:

- document the realities around the life situation of disabled children, comparable at national and regional levels, to enable the planning, implementation, monitoring and evaluation of inclusive policies;
- encourage policy makers and all stakeholders to design mechanisms to ensure that the participation of disabled children is equal to that of non-disabled children;
- promote inclusive development to enable all people to have equal opportunities to participate in the economic and social development of their societies.

Consequently, a cohort of approximately 540 Ethiopian children aged 9-17 with physical, visual, hearing and intellectual disabilities were interviewed for this study, as well as their primary carers. The respondents were questioned on many aspects of their daily life and living situation (both factual and perceptual) as a child with a disability or as the carer of a disabled child. This information was supplemented using data collected from interviews with other stakeholders – community leaders, health care workers and teachers – focus group discussions with disabled young people, and through a

new qualitative method named *A day in the life*: each respondent received a disposable camera to document an average day in their life, and then they took them with an interviewer. Each respondent received a camera to document the photos and the reasons they took them with an interviewer.

## 2. Study context

### 2.1 Ethiopia and how it functions

The Federal Democratic Republic of Ethiopia was established in 1992 and has been ruled by the Ethiopian People's Revolutionary Democratic Front (EPRDF) since the fall of the socialist regime in 1994.

Administratively, the country is divided into nine semi-autonomous *kililoch* (regions) and two chartered cities, divided along ethno-linguistic lines. Each region is subdivided into a number of zones (68 in total), within which are *woredas* (districts) and

*kebeles* (neighbourhood associations) (CSA 2008).

The 2007 census estimated the current population of Ethiopia at 73.9 million (50.5% male, 49.5% female); the United Nations Development Programme has projected that it will grow to 108 million by 2020 (UNDP 2009).

Over 80 ethnic groups were listed in the census, 10 with populations of over 1 million. The two most populous ethnic groups are Oromo (32% of the total population) and Amhara (30%), followed by the ruling ethnic group Tigrie (6%) and Somali (6%) (CSA 2008).

Figure 1: Map of Ethiopia



Source: [www.younglives.org.uk/countries/ethiopia](http://www.younglives.org.uk/countries/ethiopia)

According to the 2007 census, the major religious denominations in Ethiopia are Orthodox Christianity (44%), Muslim (34%) and Protestant (19%), with Catholic, traditional and others making up the remaining 3% of the population.

The UNDP's 2009 *Human development report* ranks Ethiopia 171<sup>st</sup> out of 182 countries with a human development index of 0.414. This broad wellbeing indicator takes into account monetary and non-monetary wellbeing including health care, education and purchasing power. The report puts Ethiopian life expectancy at birth as 55, with a 27.7% chance of not surviving beyond the age of 40. Gross domestic product per capita is US \$779 (UNDP 2009).

United Nations fast track initiative data estimates Ethiopia's net primary enrolment rate in 2008 at 91%<sup>2</sup>, a figure that is also quoted by Ethiopia's third education sector development plan (ESDP III). However, World bank figures for 2007 put the combined gross enrolment ratio at 49%; the education index at 0.4%; and the human poverty index rank at 130.

Census results of 2007 place the adult illiteracy rate (for people aged 15 and above) at 64.1%, and the population living below the national poverty line at 44.2%. For the same period, the government's expenditure on health was 10.6% of total government spending, while expenditure on education represented 23.3%.

## 2.2 Overview of disability in Ethiopia

The 2007 census estimates that the prevalence of disability in Ethiopia is 1.09%. However, this result is widely believed to significantly underestimate the true figure. The census excluded homeless people (an estimated one-in-three street children have a disability), while social stigmas and ignorance often prevent disabled people and their families from self-identifying (Mont 2007). In contrast to the 1994 census (which estimated a prevalence of 1.95%), the 2007 census excluded short-term difficulties due to temporary conditions, so persons with limited vision or hearing who were considered to perform activities 'within the range considered normal for a human being' were not classified as disabled. Leprosy, epilepsy and intellectual or learning disabilities (with the exception of severe mental impairment) were also excluded.

Poverty, ignorance, war and drought were cited in the 1994 census as the major causes of disability in Ethiopia, aggravated by inadequate nutrition, limited access to health care and educational services and the high prevalence of harmful traditional practices such as child marriage and female genital mutilation (MoLSA 1996).

Handicap International describes discrimination against disabled people as being influenced by three factors:

---

2 <http://www.educationfasttrack.org/newsroom/focus-on/fti-annual-report/>

attitude (including culture and religion); environment (physical inaccessibility); and institutional (legal) discrimination. Arguably, disabled children in Ethiopia face all three sub-discriminations, with disability linked to social and familial rejection, lack of education and employment opportunities and feelings of shame. Children with disabilities are seen as unproductive burdens on the family, and traditional beliefs prevail that disability is the consequence of a curse or wrong-doing committed by the family.

As a consequence of these stigmas, children with disabilities are often hidden at home and due to a lack of official birth registration and negative perceptions, may remain hidden from society or social workers for years. Disabled children are frequently exploited and denied their rights to education, participation in the family and community, employment and independence. Tirussew (2006) states that this lack of acceptance and interaction from family and society puts disabled children at a higher risk of psycho-social malfunctioning; it also has critical impact on their emotional wellbeing and capacity to succeed in educational and occupational environments.

The ministry of education puts the school-age population of Ethiopia at approximately 15 million, of which

1.5 to 3 million have special needs<sup>3</sup> (Ministry of education 2005). It is also estimated that less than 1% of children with special needs in Ethiopia currently have access to primary education (Asrat 2010). Tirussew (2006) states that children with disabilities have always been included in the traditional, verbal, Orthodox priest-taught Ethiopian education system, and that the marginalisation of disabled children rose in recent years as a consequence of modern, written education techniques. However, despite a lack of quality data, anecdotal evidence suggests that a low percentage of children with disabilities have had access to any education, traditional or modern.

A background report on inclusive education in Ethiopia prepared for the Education for All *Global monitoring report 2010* stressed that a lack of sign language skills and special needs training among teachers, and inadequate accessibility of schools and teaching materials, prevented disabled children from accessing education. The report also points to the severe lack of early childhood development programmes for preventing the early diagnosis of disabilities. Although adequate figures do not exist, the report suggests that this may be instrumental in the high numbers of disabled children repeating or dropping out of school (Lewis 2009).

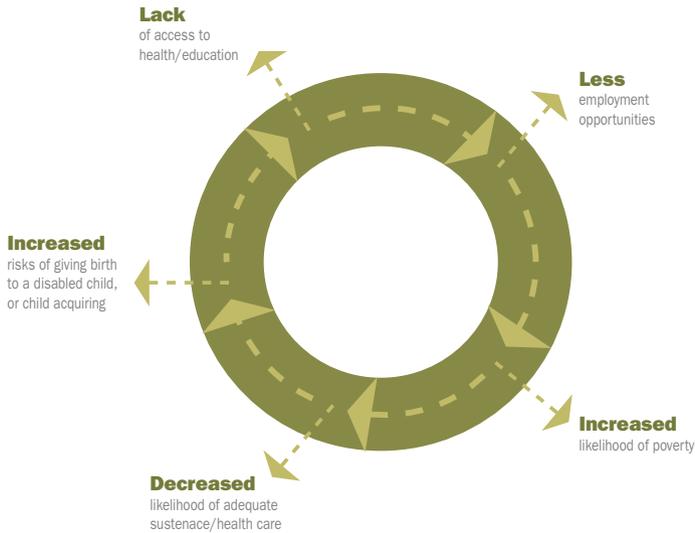
---

3 The term special needs is not defined in the referenced document, but is taken to refer to children requiring additional learning assistance, for reasons including: challenges with learning and communication; emotional and behavioral disorders; physical disabilities; and developmental disorders.

*“Poverty is not simply the consequence of a lack of resources. Some people are unable to access existing resources because of who they are, what they believe or where they live. Such discrimination is a form of exclusion and a cause of poverty”.*

**Yeo 2001**

Figure 2: The link between disability and poverty



Although there are no official statistics, the link between poverty and disability in Ethiopia (depicted in Figure 3) is presumed to be strong.

Disabling factors in Ethiopia are strong at the prenatal, perinatal and postnatal stages (Tirussew 2006), and include:

- the health of prospective mothers;
- delivery options available to women;
- childhood infectious diseases;
- under- or malnutrition;
- harmful traditional practices;
- lack of proper child management;
- poor maternal or early childhood hygiene and sanitation;
- the absence of sufficient preventative services or awareness.

Support for disabled children remains minimal in Ethiopia: parents often state that they have difficulty in procuring meaningful information about the nature and prognosis of the disabilities afflicting their children, as well as little access to emotional or financial support networks (Chernet 2007).

Religious gatherings continue to promote the giving of alms to disabled people, prolonging the misconception that disability is a charity issue.

Intellectual disability in particular is still widely misunderstood in Ethiopian

society, and seen to be an incredible burden on the family. A larger proportion of children with intellectual disabilities are found in institutions than those with other disabilities, and again, while there is no official data, anecdotally they are known to have the lowest access to education, independence, employment and participation. 2.3 Legislation and policies that guard the rights of children and adults with disabilities in Ethiopia

### 2.3.1 Summary of major legislation

Table 1: Summary of major legislation and policies that shape the provision of services for children with disabilities

<b>Major national legislation that underlies the provision of disability services</b>	
<ul style="list-style-type: none"> <li>• The Federal Democratic Republic of Ethiopia constitution.</li> </ul>	
<b>International conventions that place an obligation on the government to protect the rights of children with disabilities</b>	
<ul style="list-style-type: none"> <li>• UN Convention on the Rights of the Child (ratified in 1991);</li> <li>• UN Convention on the Rights of People with Disabilities (ratified in June 2010).</li> </ul>	
<b>Legislation and policies of key government departments</b>	
<b>Health</b>	<ul style="list-style-type: none"> <li>• MoLSA national plan for the physical rehabilitation sector in Ethiopia (currently in draft form);</li> <li>• Health sector development programme (HSDP-III) 2005/6-2009/10.</li> </ul>
<b>Labour and social affairs</b>	<ul style="list-style-type: none"> <li>• MoLSA developmental social welfare policy (1996): focuses on inclusion, participation (in political, economic and social activities) and independence of disabled people;</li> <li>• Ethiopian building proclamation (no 624/2009): concerns physical access of disabled people to public buildings;</li> <li>• Ministry of finance and economic development plan for accelerated and sustained development to end poverty (PASDEP) 2005/06-2009/10.</li> </ul>
<b>Employment</b>	<ul style="list-style-type: none"> <li>• The federal civil servant proclamation (no 515/2005): focuses on the need to provide special attention to candidates and employees with disabilities;</li> <li>• Proclamation concerning the rights to employment for people with disabilities (no 568/2008): focuses on ensuring equal employment opportunities to disabled people.</li> </ul>
<b>Education</b>	<ul style="list-style-type: none"> <li>• Education sector development programme III (ESDP III) 2005/6-2010/11;</li> <li>• Ministry of education and training policy 1994;</li> <li>• Ministry of education SNE programme strategy 2006;</li> <li>• Ministry of education SNE in technical and vocational educational training (TVET) framework document 2009.</li> </ul>

### 2.3.2 Expansion on constitutional rights, department mandates and policies

#### a) Constitutional rights and department mandates

- Disability is mentioned specifically in the 1995 constitution only in Article 41 on economic, social and cultural rights: *“The State shall, within available means, allocate resources to provide rehabilitation and assistance to the physically and mentally disabled, the aged, and to children who are left without parents or guardian”*.
- Article 41 of the constitution also states that *“Every Ethiopian national has the right to equal access to publicly funded social services”*.
- Article 25 on the right to equality does not include disability in its list of reasons not to discriminate – which does include gender, race, etc.
- Article 9.4 states that *“All international agreements ratified by Ethiopia are an integral part of the law of the land”*.
- Disability is covered in the mandate of the department of rehabilitation affairs, under the ministry of labour and social affairs.
- Regional bureaus of labour and social affairs (BoLSAs) are responsible in the regions for *“mobilising public and private services to promote the integration of persons with disabilities”* (Asefa 2008).

#### b) International policies

- Article 2.1 of the UNCRPD stipulates that: *“States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children”*.
- Article 23 of the UNCRC stipulates the requirement of the state to recognise the rights of children with disabilities to a full and decent life, including participation in their communities and special care where needed.

#### c) Disability-specific country policies

- In 2005, Ethiopia launched its SNE strategy, in an attempt to facilitate the education of children with disabilities into the ESDP III and achieve universal primary education, one of the 2015 millennium development goals. The document stresses the need for well trained SNE teachers, to increase the return rate of disabled children to education. However, results have been less than satisfactory.
- According to the government's proclamation no 568/2008 on the rights to employment of disabled people, a *person with disability* refers to an individual whose equal employment opportunity is reduced through social, economic and cultural discrimination as a result of physical, mental or sensory impairments (Asefa 2008). The law forbids employers from

discriminating against persons with disabilities, and requires their provision of appropriate working and training conditions, particularly for women with disabilities and those in need of assistants to facilitate their work.

- The federal civil servant proclamation no 515/2007 mandates preferential treatment for disabled people in

the recruitment, promotion, and deployment of civil servant jobs in government offices only.

- The Ethiopian building proclamation no 624/2009, Article 36 specifically addresses the accessibility of design and construction of public buildings for physically impaired persons.

## 2.4 Inclusivity of children with disabilities in mainstream national policies

Table 2: Mainstream national policies that refer to inclusivity of disabled children

Sector	Key sector policy	Achievements regarding children with disabilities	Failures regarding children with disabilities
Poverty reduction	Plan for accelerated and sustained development to eradicate poverty PASDEP 2005-2010	A second PASDEP is currently being generated, which aims, with the assistance of several NGOs (notably CBM and PANE), to address the rights of disabled people for the first time. It will be presented to the House of Representatives in November 2010.	The first PASDEP was not seen to be inclusive of disabled children, but the disability-inclusive PASDEP aims to rectify this in late 2010.
Education	Education sector development programme III ESDP III 2005/6 -2010/11	The mission of the 53.7 billion birr ESDP III is to “see all school-age children get access to quality primary education” by 2015, and to be responsive to the country’s PASDEP strategy of agriculture-led industrial development.  An estimated 15 NGO-operated special schools and 285 special classes attached to regular government schools serve disabled children across Ethiopia.	ESDP III recognises that 10-20% of primary school-aged children in Ethiopia may require SNE. However, SNE is not included in regional or woreda level plans and budgets, and is given a 0.01% share of the total ESDP III financial budget.

continued...

Sector	Key sector policy	Achievements regarding children with disabilities	Failures regarding children with disabilities
Education		<p>The 2005 SNE strategy places responsibility for educating disabled children with regional woreda education offices, and attempts a triple strategy of mainstreaming disability in regular schools, incorporating special units in regular schools and building special schools. The strategy also includes new masters degrees in SNE at several Ethiopian universities, aimed at increasing capacity at various levels, and the development of guidelines for curriculum and institution modification to facilitate disabled children.</p>	<p>Disappointing SNE results include a lack of:</p> <ul style="list-style-type: none"> <li>• awareness among regional educational bureaus and woreda education offices of their responsibilities to ensure universal access;</li> <li>• ability of the same bodies to ask for assistance from the ministry of education to do the above;</li> <li>• systems for guidance or assistance for SNE officials;</li> <li>• reporting mechanisms for success and failures.</li> </ul>
Health	<p>Health sector development programme HSDP-III 2005/6-2009/10</p>	<p>The mission of the HSDP is to <i>“reduce morbidity, mortality and disability, and improve the health status of the Ethiopian people through providing a comprehensive package of preventive, promotive, rehabilitative and basic curative health services via a decentralised and democratised health system in collaboration with all stakeholders”</i>.</p> <p>Health centre key activities that include screening of school children for chronic illness and disability.</p> <p>MoLSA currently runs six orthopedic centres across the country.</p>	<p>The lack of available data on the successes of HSDP III related to disability is not encouraging.</p>
Social grants	<p>Productive Safety Net Program 2005-2010</p>	<p>Provides transfers to over 8 million food-insecure beneficiaries, through labour-intensive public works schemes and direct transfers for labour-poor households (including the chronically ill and people with disabilities).</p>	<p>Some scholars have cautioned that children are substituting for adult labour in the public work schemes, impacting on their education. No specific data on children with disabilities is available.</p>

## 2.5 The role played by non-governmental organisations

Ethiopia has a sizeable CBR sector, with at least one NGO present in almost all regions of the country. These include local offices of international NGOs – such as Handicap International, Cheshire Foundation Ethiopia and Cheshire Services Ethiopia – and local NGOs such as RAPID Adama, Addis Development Vision and Arba Minch Rehabilitation Centre.

Encouragingly, many NGOs working on disability issues in Ethiopia are strongly connected to their respective BoLSAs. In a reciprocal relationship, the BoLSAs often provide financial support to the NGOs and disabled persons' organisations (DPOs) in exchange for technical support to the BoLSAs and their district offices. The best example of this integration is CBM (an international Christian development organisation) in Tigray region, which runs a CBR programme in partnership with the bureaus of health, education, agriculture and labour and social affairs.

Ethiopia also supports a strong network of national DPOs – organisations made up of persons with disabilities – many of which have regional branches. These include:

- Ethiopian National Association of the Deaf (ENAD);
- Ethiopian National Association of the Blind (ENAB);
- Ethiopian National Association of the Physically Handicapped (ENAPH);
- Ethiopian National Association for

Intellectual Disability (ENAID);

- Ethiopian Women with Disabilities National Association (EWDNA);
- Federation of Ethiopian National Associations of Persons with Disabilities (FENAPD);
- Ethiopian National Disability Association Network (ENDAN).

CBR NGOs primarily focus on providing medication, medical care, physiotherapy, assistive devices, rehabilitation, care and advice to children with disabilities and their families. The sector is expansive, and in some towns like Bahir Dar, there are as many as one CBR worker per kebele working for organisations such as Cheshire Foundation. Though medically based, these NGOs are often also involved in numerous activities. The following examples show some of the best practices in Ethiopia from CBR NGOs and DPOs:

- Baseline surveys: Several NGOs have conducted baseline surveys and needs assessments in their respective areas, including Cheshire Services (Hawassa), Handicap International (Dire Dawa) and CBM International (Mekele) – the latter in partnership with the Tigray BoLSA;
- Community sensitisation and awareness-raising: Numerous NGOs and DPOs are involved in community sensitisation using different methods – such as child-to-child programmes, group education in schools, disability awareness clubs, parents' groups and university student bulletins on disability – to promote inclusion;

- DPO start-up: Some NGOs, such as the RAPID Adama CBR project, have been actively involved in establishing new DPOs in their regions;
  - Economic empowerment: Several NGOs have provided small grants or loans to aid economic empowerment and small business start-up capital to carers of disabled children. For example, Cheshire Services (Dire Dawa) recently provided start-up capital for a group of mothers of disabled children to open a canteen in the local police compound, which they run while their children are at school;
  - Legal aid: ENAPH (Dire Dawa) provides legal aid to families of children with disabilities;
  - Vocational training and special education units: Many DPOs and NGOs aim to enhance the employability of disabled people through vocational training, and provide support to local schools to help them meet the educational needs of disabled children. For example, Arba Minch Rehabilitation Centre has built nine special education units in the region and trained teachers in SNE and sign language interpretation with funding from local government. ENAB (Dire Dawa) recently inaugurated a vocational skills training centre and library for disabled people, with funding from Handicap International;
  - Education training materials: Many NGOs and associations provide support to disabled children and their carers to help keep the child in school. This includes equipping disabled children with pens, books and uniforms, and providing financial and non-financial assistance and information to carers to ensure the child is able to continue learning;
  - Informal education: Cheshire Foundation (Bahir Dar) is carrying out house-to-house screenings for disabled children in urban kebeles and providing basic, informal education for any children who are not enrolled in formal education.
- Despite these examples of best practice, there is a major gap in Ethiopian NGO support for disabled children: street children. While orphaned or abandoned children are cared for by a number of religious institutions – such as the Missionary Charities of Brothers and of Sisters or the SOS childrens’ homes – children who are unable to, or choose not to, enter such facilities often end up begging on urban streets. Although several NGOs – such as the Forum for Sustainable Child Empowerment (FSCE) – work with street children, few have the mechanisms in place to include and support disabled children. A handful of small operations – such as Zenebwork Sheltered Homes – provide temporary lodging for disabled street children, but income-generating activities, including vocational and skills training and small business start-ups, are not made available and accessible to them.

### 3. Research methodology

#### 3.1 Preliminary activities and research design

The research team consisted of members of ECDD and ACPF and an independent disability consultant. The team spent several months deliberating over the final research methodology design, and designing the research instruments, with inputs from international child and disability experts and a panel of stakeholders consisting of members of local disability organisations, relevant ministries and NGOs. The international disability experts were contacted for their comments and validations before the instruments were used.

Prior to the main data collection, the team conducted a pilot study (of 32 respondents) in Addis Ababa, to test the research instruments and methodology, making several alterations to streamline them both as a result.

All child and adult respondents of both the pilot and the main study were informed in detail about the research objectives and outputs, and requested to sign a consent form. Anonymity has been preserved, and permission was sought for the usage of all photographs in the report.

#### 3.2 Quantitative data collection

Survey interviewers, data collection facilitators and disability field workers were identified in each region through a network of contacts in local government, disability NGOs and DPOs. Data collection facilitators were responsible for identifying respondents in compliance with the strict sample criteria, which include age, sex, and disability type. The disability field workers, who were known personally to the respondents, explained the research objectives to the children and their carers and introduced them to the survey interviewer. The purpose of this was to ensure that all respondents were made adequately aware of the research purposes and outcomes prior to interview.

Survey interviewers undertook a two-day training course on the research design and instruments, and were supervised during preliminary interviews. Prior research skills were seen to be an asset, and experience of working with disabled children and positive attitudes towards disability were compulsory.

Data was collected from the four most populous regions of Ethiopia, and two chartered cities. There was some overlap between the factual and perspective data in the carer and

child questionnaires, to determine correlation of facts and understand whether the carers had different perspectives from the children.

The main sections of the child questionnaire were:

- background information: how and when they acquired their disability;
- health and wellbeing: independence in performing specific tasks and the accessibility of their environment;
- education: their experiences (or lack) of education, including perceived learning outcomes and relationships with teachers and peers;
- work: paid and unpaid work or chores they are involved in; perceptions of the role of work in their current and future lives;
- attitudes and views: their own beliefs regarding their disability; the reaction of their family, community and society to their condition; and their outlook on the future.

The main sections of the carer questionnaire were:

- background information: whether the child's birth was registered; how and when the child acquired his or her disability; and household composition;
- housing condition and accessibility: the structure, sanitation and physical accessibility of the dwelling, and the independence of the child within his or her own home;
- participation: the carer's perspective on the child's role and participation in the family and community;

- education: whether the child was enrolled in school and the carer's perspective on the role of education in the child's life;
- health care: services available (and from whom); in cases where the child used the service, whether the carer felt it was helpful;
- income: the financial impact of the presence of a disabled child on the household;
- awareness of rights and perspectives on stigmas related to children with disabilities.

Data was collected from children in both conventional (household) and unconventional (institutions and on the streets) settings, in both rural and urban areas, to understand the full dynamics of childhood disability in Ethiopia.

### 3.3 Qualitative data collection

The study used key informant interviews, focus group discussions and an innovative qualitative method named *A day in the life* to contextualise the quantitative data: 9 key informant interviews were undertaken with 2 teachers in inclusive and non-inclusive schools, 3 community leaders, 3 health care workers and an elder.

Focus group discussions were carried out after preliminary data analysis with two key groups – disabled street children and disabled Addis Ababa University students – to raise questions about surprising findings therein.

The 'A day in the life' exercise gave four child respondents and two non-disabled children disposable cameras,

with which to document an average day in their life. The children were then interviewed, using the photos as stimuli to probe them in detail about pertinent aspects of their daily life, and to explain why they had chosen to take specific photographs.

In addition to the primary information gathered, the research includes data collected from administrative records and national and international studies, policies and laws relating to disabled children in Ethiopia. This data and information helps to contextualise the study and provides background information on the environment in which the respondents live, enriching the analysis and policy recommendations that emerge from our primary data analysis.

Given that the qualitative instruments used in the study were semi-structured, the qualitative interviewers had a background in social research or anthropology, and were familiar with and positive towards disability issues.

### 3.4 The sample

Although the team hired the field personnel to ensure strict adherence to the sample design, the response was slightly short of the 540

requested, with 471 carer and 497 child questionnaires returned. Given the tight time frame, the research team had to use this data and could not send interviewers to repeat the task.

The number of child and carer questionnaires do not correspond exactly for several reasons. For example, in some households with intellectually or hearing-impaired children, it was not possible to communicate directly with the child, meaning that only a carer questionnaire was conducted. In other situations, such as when interviewing children on the street, in institutions or when they are the heads of households themselves, there was no relevant carer to question alongside the child.

Tables 3 and 4 show the number of questionnaires returned by disability and gender, and whether or not the child was in a conventional or unconventional setting. Multiple disabilities were most frequently visual plus physical, or visual plus intellectual. The sample was 43% rural and 57% urban. Excluding official sign language interpreters, 28% of child interviews were held in the presence of another person; the main reasons for this were for communication (63%), to aid the child's attention (26%) and to calm the child (8%).

Table 3: Breakdown by gender and disability type for returned child questionnaires

		Disability type					Total
		Physical	Visual	Hearing	Intellectual	Multiple	
Conventional setting	Male	52	53	62	40	6	213
	Female	65	49	57	43	6	220
	Total	117	102	119	83	12	433
Institution	Male	8	6	3	5		22
	Female	6	5	5	4		20
	Total	14	11	8	9		42
Street	Male	3	4	3	2		12
	Female	4	1	3	2		10
	Total	7	5	6	4		22
Total % of sample (count)	Male	63	63	68	47	6	49.7% (247)
	Female	75	55	65	49	6	50.3% (250)
	Total	28% (138)	24% (118)	27% (133)	19% (96)	2% (12)	100% (497)

Table 4: Breakdown by child's gender and disability type for returned carer questionnaires

		Disability type					Total
		Physical	Visual	Hearing	Intellectual	Multiple	
Conventional setting	Male	51	42	63	48	11	215
	Female	60	43	60	52	8	223
	Total	111	85	123	100	19	438
Institution	Male	4	3	3	5	5	20
	Female	2	1	5	4	1	13
	Total	6	4	8	9	6	33
Total % of sample (count)	Male	55	45	66	53	16	49.9% (235)
	Female	62	44	65	56	9	50.1% (236)
	Total	25% (117)	19% (89)	28% (131)	23% (109)	5% (25)	100% (471)

### 3.5 Study limitations

The team notes several limitations to the study throughout the project process, which are detailed in this section.

- The team discussed the importance of including children *without* disabilities in the main analysis, for comparison purposes. However, budget constraints prevented children without disabilities from participating in the quantitative data collection. The qualitative analysis, on the other hand, focused on comparison between children with and without disabilities, including the *A day in the Life* tool, which provided an in-depth look at an average day in the life of case-study children with and without disabilities living in the same physical and socio-economic environment.
- Only children aged 9-17 were interviewed. Children aged eight years and younger were not included largely due to the ethical considerations affecting young children in unconventional settings, and to minimise the possibility of misinformation which may have arisen from carers or other third parties responding on their behalf.
- Children with profound intellectual disabilities that prevented them from communicating verbally were also predominantly excluded from the survey, again due to the

risk of misinformation from third parties responding on their behalf. Instead, only children with moderate intellectual disabilities, who could communicate with the researchers – either independently or with assistance – were selected for the study. Children incapable of verbal communication are particularly vulnerable, and documenting their situation is of great importance. The team therefore hopes to conduct further study in this area, using specially designed, interactive research instruments to accommodate non-verbal communication by children with profound intellectual disabilities.

There is a major lack of quality information on the location of disabled children across Ethiopia's population, due to the poor screening of disability in national censuses and early education, as well as the lack of birth registration and up-to-date hospital records. Consequently, the research identified respondents using a snowball-sampling process, through NGOs, local government offices and special or inclusive schools, all of whom worked with children with disabilities. This means that the sample predominately includes disabled children who are already participating in CBR programmes or in education.



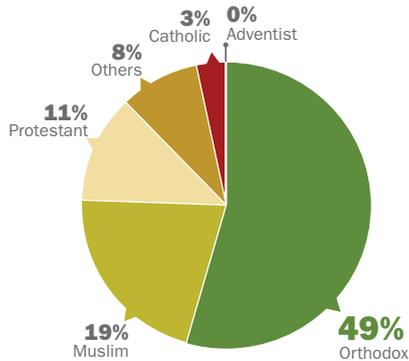
## 4. Results of the survey

### 4.1 Profile of childhood disability

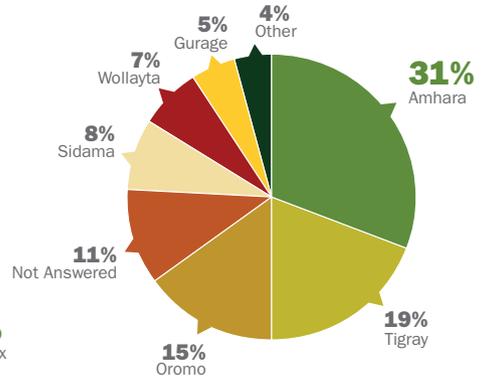
#### 4.1.1 Distribution

The profile of respondents – by religion and ethnicity – are shown in Graphs 1 and 2.

Graph 1: Religious profile of child respondents



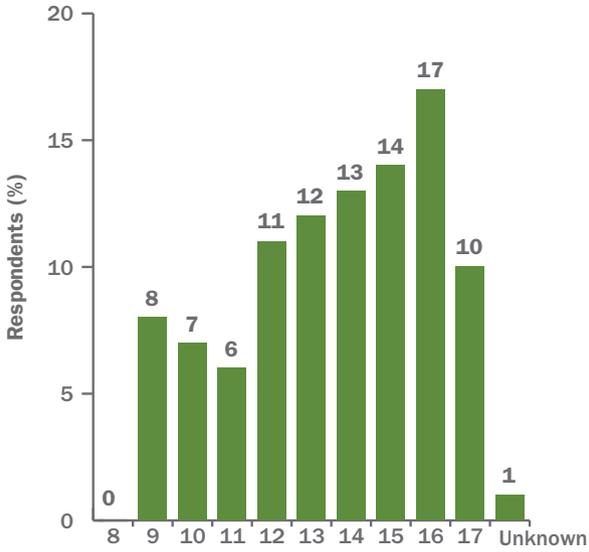
Graph 2: Ethnic profile of child respondents



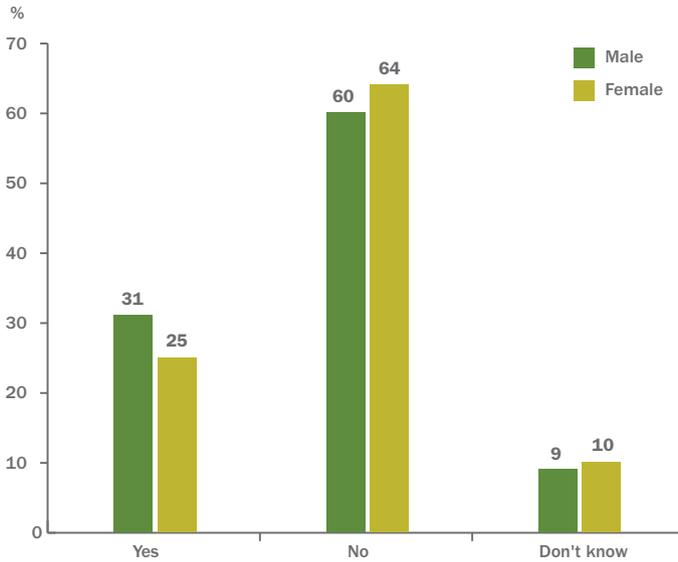
The average age of child respondents was 14. Six children (two from institutions, three from urban families and one from a rural family) did not know their ages. Worryingly, only 28% of respondents' births (31% of boys and 25% of girls) had been registered.

The lack of birth registration in Ethiopia significantly hinders the ability of health care workers and other agents to identify and monitor early childhood development and disability support, and should be immediately addressed.

Graph 3: Age profile of child respondents



Graph 4: Birth registration of child respondents

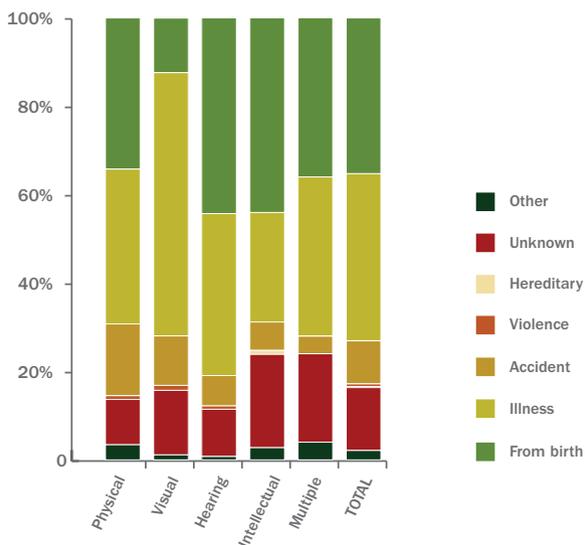


### 4.1.2 Cause and onset of disability

According to carers, 35% of the children in the study had been born disabled, 38% had been disabled through illness, 10% through an accident, 1% through violence, less than 1% through hereditary causes, 2% through other means (stated as God’s curse, punishment of sins and evil

spirits) and 14% for unknown reasons. A lack of accurate documentation on childbirth and the onset of disability hinders the effective prevention and cure of childhood disability. It is important therefore to increase birth registration and the recording of pertinent early childhood information for statistical purposes, to monitor the effectiveness of public health policies both in general and concerning children with disabilities in particular.

Graph 5: Cause of disability, by disability type (carer questionnaire)

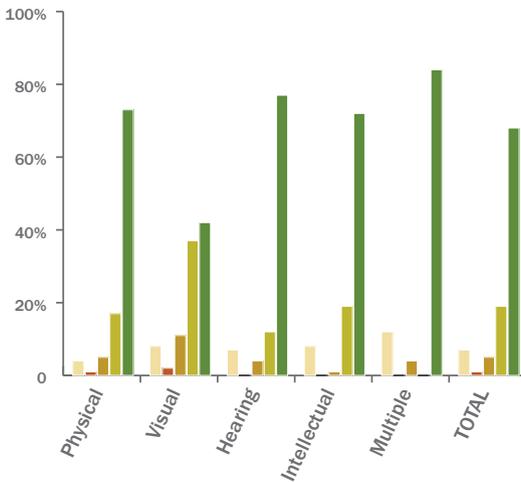
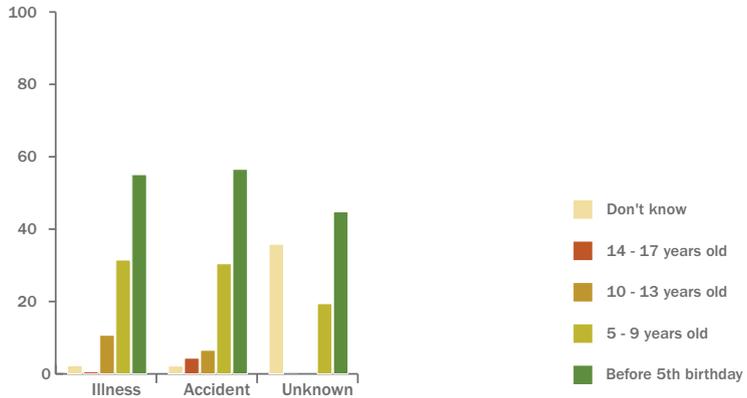


The trend is predominantly consistent across all disability types, except for visual disability: 12% of children with a visual impairment had been born disabled, while 60% – a much larger than total sample average – had been disabled through illness. This is reflective of the large incidence of preventable visual disability in Ethiopia as a consequence of trachoma,

glaucoma and other infectious diseases. It is also reflective of the lack of access to primary health care (see Section 4.3.5), and its negative impact. A comparatively larger percentage of children with physical disabilities (16%) were disabled through accident, compared to the total average of 10%. It is of concern that 14% of primary carers were not aware of the cause of their child’s disability.

The child respondents gave they had acquired their disabilities approximately similar answers, (21%). This coincided with a smaller deviating only in the higher number of proportion accrediting their disability to birth or illness (31% and 34% respectively).

Graph 6: Age onset of disability, by cause and disability type

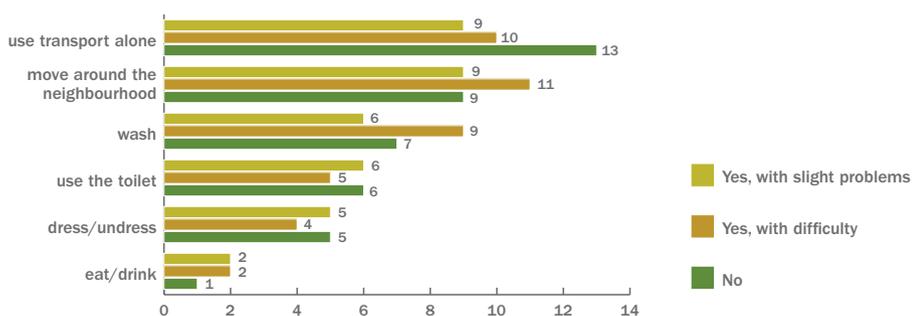


According to carers, 68% of disabilities were acquired between birth and the child's fifth birthday. Children with visual disabilities were much more likely, however, to acquire their disability between the ages of 5 and 9 (37%, compared to the average of 19%). As before, slightly more children than carers (12% compared to 7%) answered that they did not know when they acquired their disabilities. Children acquiring their disabilities through accidents, illnesses or unknown reasons were all most likely to have done so before their fifth birthdays.

### 4.1.3 Limitations on functioning

This study attempted to highlight carers' perceptions of the ability of the disabled child under their care to perform a series of activities independently, without assistance from another person or special equipment: 54% of responses were positive, while the activities were considered to be impossible for 10% of children, and possible with slight or major difficulty for 15%.

Graph 7: Ability of disabled children to carry out certain tasks and activities (carer questionnaire)



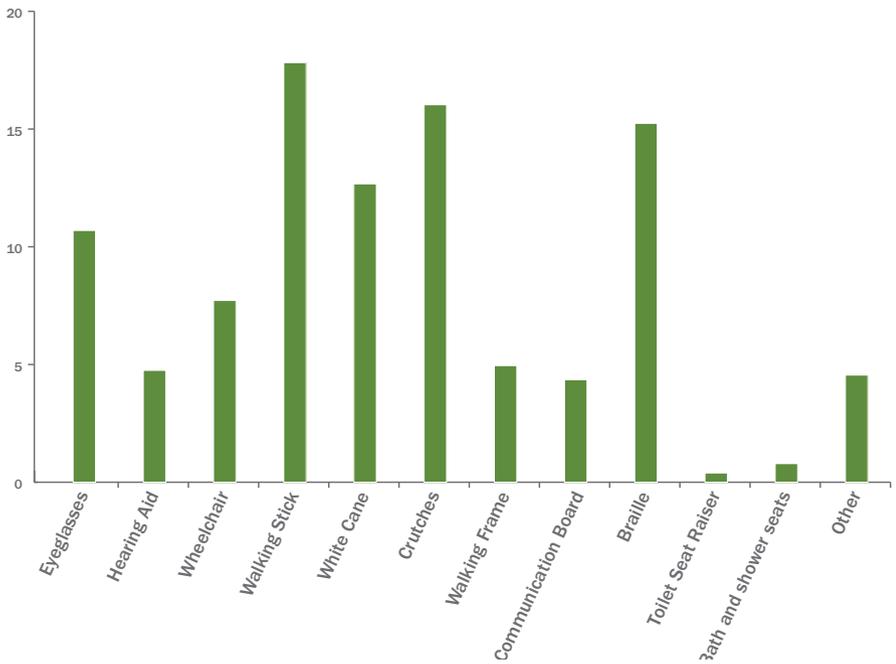
Graph 7 shows that significant number of the children can not carry out some of the activities at all without a help either from a person or a device: 13% can not use transport alone, 9% and 5% can not wash and dress/undress themselves respectively. The children rated their abilities to carry out the activities very similarly to their carers, but rated their ability to perform almost

all activities slightly higher, with 59% answering that they could perform the activities independently and with no difficulty, 13% saying the activity was possible but with either slight or major difficulty, and 8% saying that the activity was impossible. This finding is important, as it stresses the false belief of many carers that the children under their care are incapable of performing certain tasks independently.

Of the children who said they needed assistance, 66% needed assistance from a person, 19% needed assistance from a device and 15% needed assistance from a person and a device. The most common devices were crutches (16%), braille (15%) and walking sticks (18%). With the assistance of either a person or an

assistive device: 18% no longer had a problem; 66% still had a problem, but found it had improved; 15% said the problem had not improved; and less than 1% felt the problem had got worse. This implies that providing an assistive device or training a person on ways to assist the child under their care can significantly improve the child's ability to function.

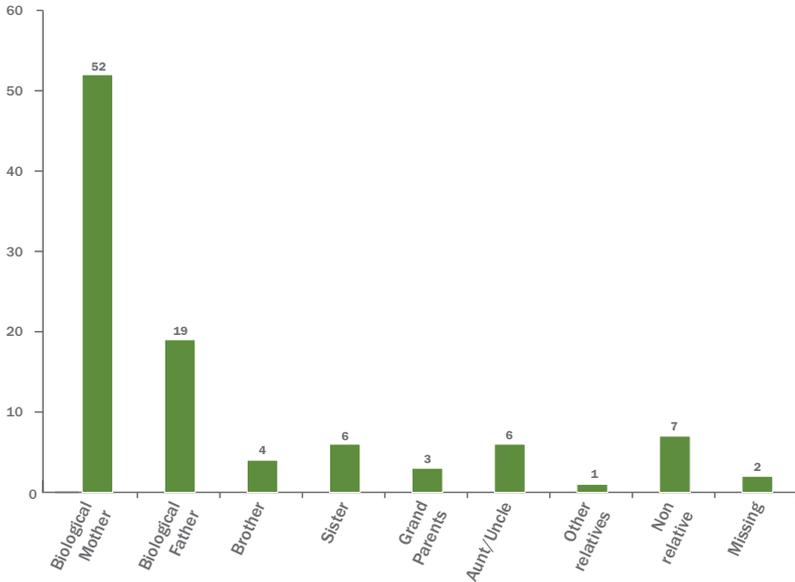
Graph 8: Assistive device needed by child respondents



## 4.2 Household and family dynamics

### 4.2.1 Family dynamics

Graph 9: Relationship of primary carers to the disabled child in their care



Seventy-one per cent of respondents to the carer questionnaire (the child's primary carer) were female. However, even though most of the respondents are female and some male primary caretakers were not available to respond to the questionnaires, 40% of boys and 18% of girls were primarily cared for by a male.

The average age of male carers was 44, while the average age of female carers was 39. Encouragingly, less than 2% of primary carers were under 18.

The vast majority – 71% – of primary carers were the child's biological mother or father; 7% were not related to the child – of these, 36% were in conventional setups, and 64% in institutions.

The children were asked about a set of situations in relation to the impact of their disability on their position within their families or households, and whether the situations always, sometimes or never happened to them. A large majority of children believed that the family did not spend more time (66%) or money (73%) on

them because of their disabilities. Only 27 % felt that their disability was the cause of fighting within the family.

Disabled street children who participated in a focus group discussion revealed that they formed their own family units with other children on the streets, and that members of these groups supported each other emotionally and financially.

### 4.2.2 Dwelling

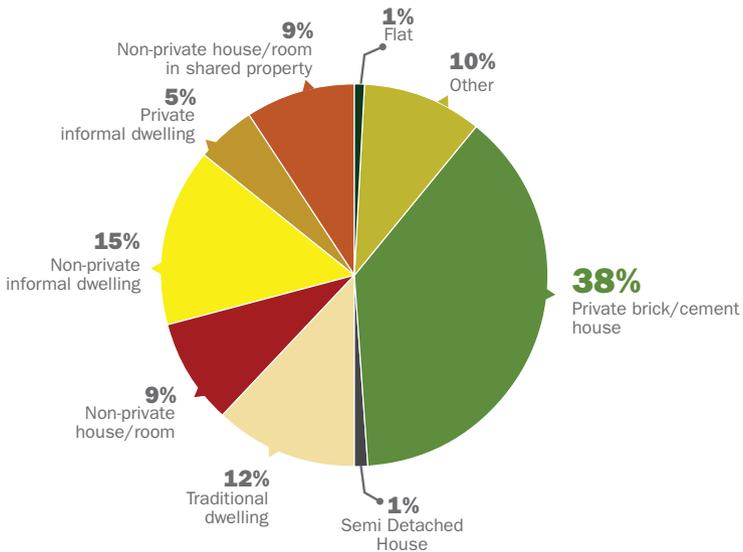
Thirty-eight per cent of the child respondents lived in private houses made of brick or cement, with their own yards; 15% in non-private informal dwellings in other people’s yards; and 12% in traditional dwellings made of mud or other traditional materials. The 10% living in “other” accommodation

were mainly in institutions and care homes.

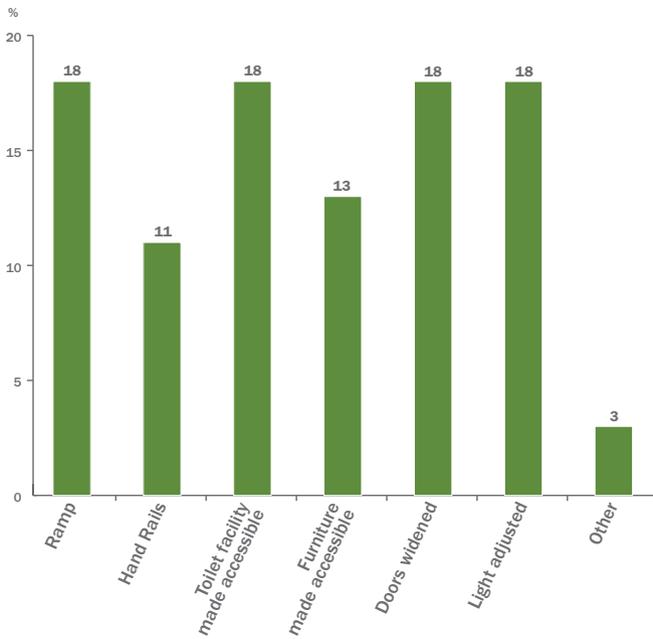
Only 13% of carers stated that their houses had been physically adapted to assist the disabled child under their care. Of these, 82% were carers in conventional settings, and 18% were in institutional settings. Of those children whose housing had been physically adapted, 23% were physically impaired; 15% visually impaired; 25% hearing impaired; 28% intellectually impaired; and 8% had multiple disabilities.

Of all the adaptations, 67% were paid for by members of the household or institution, but a small number were paid for by other people outside of the family unit – including members of the community (8%) and the government (8% of institutional adaptations and 2% of private household adaptations).

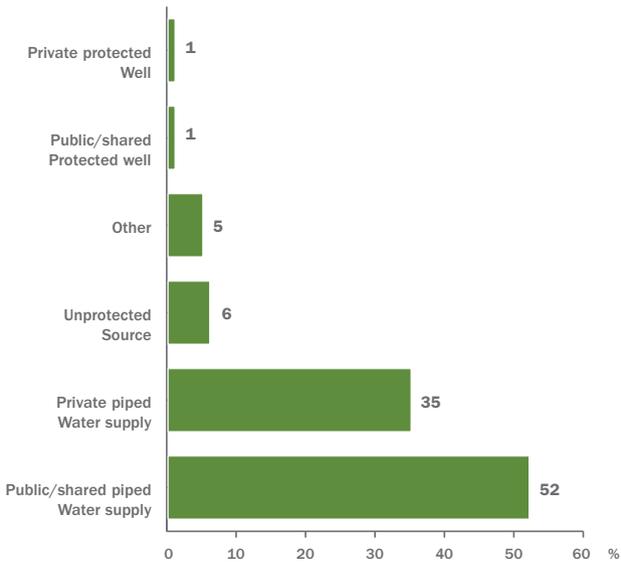
Graph 10: Where child respondents live



Graph 11: Adaptations to dwellings (by dwelling type)



Graph 12: Primary water source for households of child respondents



The majority of the sample (52%) used a public or shared piped water supply as their main source of drinking water; 35% had access to a private piped water supply; 6% used an unprotected source (a spring, pond, river, stream, etc); 5% used another source; and less than 2% used a private or public well.

Almost half – 49% – had access to a private pit latrine; 28% to a communal pit latrine; 7% to a flush toilet; less than 1% to an ‘other’ toilet facility; and a worrying 14% had no access to a toilet facility. Lack of access to clean water and sanitation is a major cause of preventable disability from waterborne diseases, and exposes children to additional risks that cause malnutrition and stunting.

### 4.3 Access to social services and support

Children’s access to social services and support is not only determined by the availability and physical accessibility of the services but also, to a larger extent, by the prevailing attitudes towards disability and children with disabilities and the level of awareness of the children and their caretakers of their right to access services. Therefore, the discussion of access to social services and support will not be complete unless it is contextualised vis a vis the prevailing attitude and level of awareness.

#### 4.3.1 Attitude towards children with disabilities

Attitudes of family and community members in particular and the public

in general play crucial role in either creating access to services or posing barriers to services. Attitudinal barriers usually arise from negative societal beliefs about the worth of children with disabilities. This study however revealed, through focus group discussions and interviews with community leaders, that the presence of an active disability-inclusive NGO or DPO in the locality led to a major difference in attitude towards disabled children. Where there was NGO support, leaders reported positive attitudinal change throughout their communities. A focus group discussion with disabled street children in Hawassa (where several disability NGOs and DPOs are active) disclosed their reliance on the community’s material and psychological assistance to survive.

In contrast, a community leader from Mekele, which does not have a large disability network, stated that in his community, *“disability is still regarded as a curse, and anyone who gives birth to a disabled child is automatically discarded from the community”*.

*Picture 1: Henok prepares to sleep after an afternoon playing football with his friends*



The *A day in the life* exercise included two boys from the same rural community, one with a physical disability and the other without (for more information, see Appendix 2). Encouragingly, the two children had identical chores, and played together in the same way. More importantly, when the disabled child felt that his disability was hindering him, his non-disabled friends reminded him of the benefits of his condition (including that he was the best goalkeeper in their team, because he knew the position well) and uplifted his spirits. This look into a day in the life of the two children showed a lack of discrimination or exclusion between children with and without disabilities, and the full capacity of a disabled child to participate in community life as his non-disabled peers. These are lessons that can be learnt by carers, practitioners and wider society alike.

*“People with disabilities are starting to believe the concept of ‘we can’ for different issues. This helps them to cope with the challenges that they are facing”.*

**Teacher, key informant, Addis Ababa**

Some key informants mentioned encouraging attitudinal changes for example, the teacher quoted in the quote above stating that teachers have observed more and more children with disabilities building in self-esteem,

self-confidence and self-assuredness regarding their equal right to education and employment.

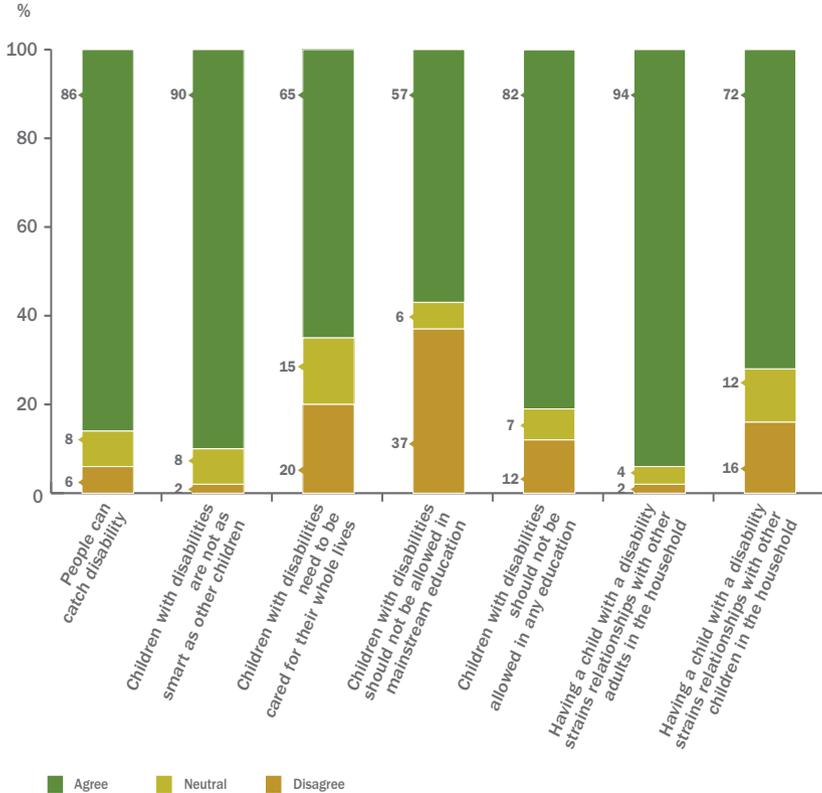
However, a less encouraging perspective was shared by a community leader in Adama, who believed the government’s negligence in educating disabled children was compounded by a lack of concern shown by their community. He hoped that community education would encourage community members to approach the government and insist on fairer treatment for children with disabilities. Challenging community stigmas and perspectives is crucial to diminishing prejudice against disabled children and ensuring their equal access to services and opportunities.

To assess the prevalence of disability-related misconceptions, carers were asked whether they agreed with several negative and false statements about disabilities. A reassuring majority of carers did not agree with the negative statements, but 6% felt that disability could be caught, and 37% felt that children with disabilities should not be allowed in mainstream education, underlining the need for substantial carer education on disability and care.

*“She can’t be independent so I don’t think there is hope for her future”.*

**Institutional carer of an intellectually disabled girl**

Graph 13: Carers' attitudes towards disability



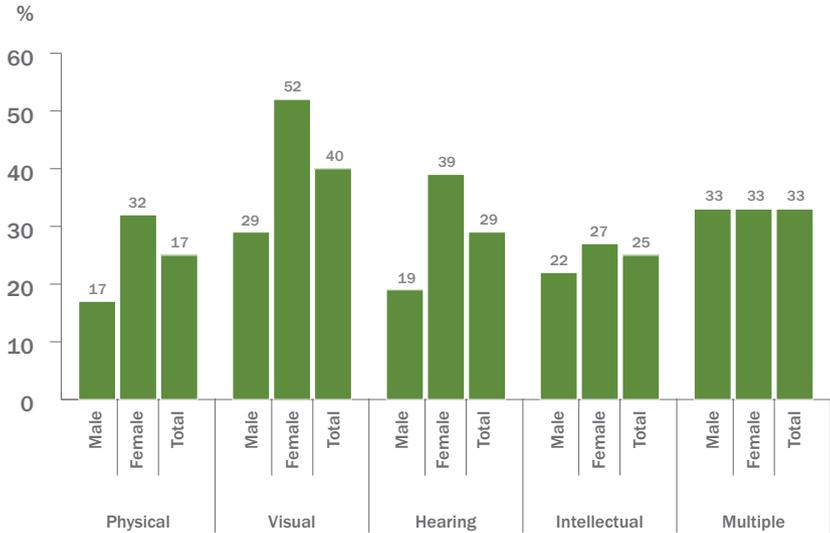
### 4.3.2 Happiness of disabled children

The level of happiness that children have can be a good indicator of their inclusion and participation within their family and community; of their independence or of the successful management of their functional limitations through the support of other persons or devices. In this study, when asked how they felt most of the time, 40% of the children said that they felt happy; 30% felt neither happy nor unhappy; and 30% felt

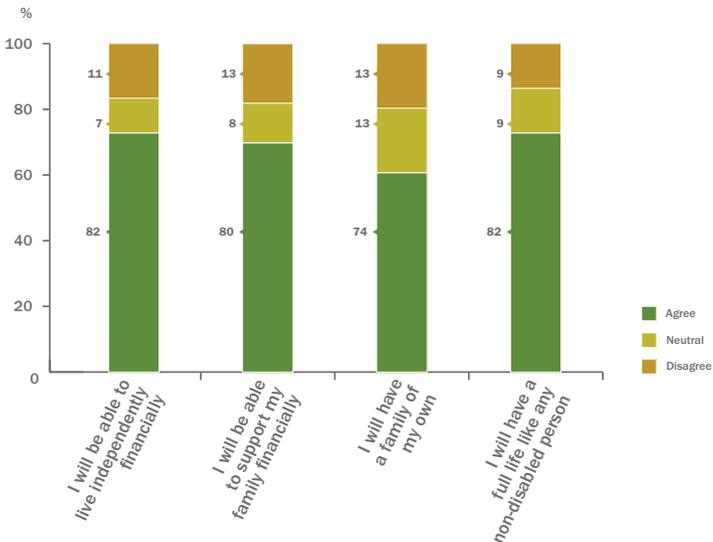
unhappy most of the time. The graph below disaggregates those who felt unhappy by gender and by disability. Girls (37%) felt less happy than boys (22%). Children with visual disabilities were the least happy (40%); followed by children with hearing disabilities (29%); and children with physical and intellectual disabilities (both 25%). The least happy group is girls with visual disabilities, with 52% stating they felt unhappy. The happiest group is that of boys with hearing disabilities (52% happy). These results highlight the need for government or NGO to employ

professionals to work with disabled children to improve their self-belief and ensure that they have the right assistance to fulfil their goals and ambitions.

Graph 14: Percentage of unhappy child respondents, by gender and disability type



Graph 15: Children's perception of future happiness



An encouragingly high proportion of child respondents were positive about their future, with 82% believing they will live independently, 80% that they will support their family, 74% that they will have a family of their own and 82% that they will have a life equal to any non-disabled person.

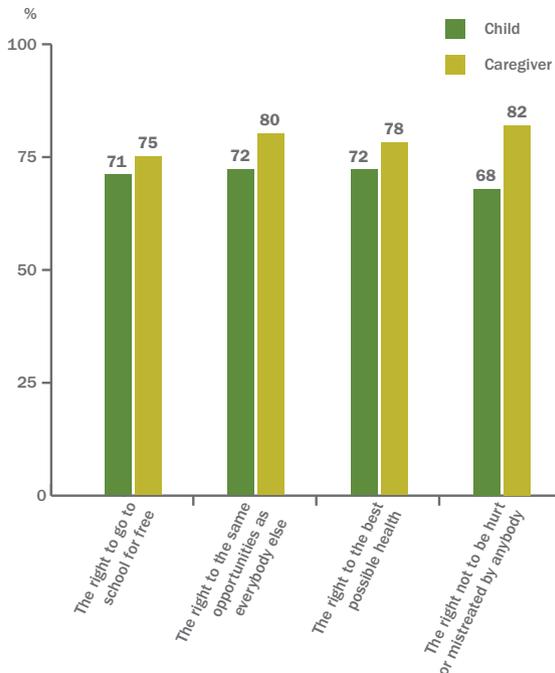
This was echoed by the carers: 79% believed the child under their care would be financially independent from them in the future; 70% believed that the child would support them as well; 80% believed the child would have a family of their own; and 82% agreed that the child would have as full a life as any non-disabled person. Of those who disagreed, 37% cared for children

with intellectual disabilities; 25% children with physical disabilities; 19% children with visual disabilities; and 12% children with hearing disabilities.

### 4.3.3 Awareness of children's rights to access services and support

The first step towards the realization of the rights of children with disabilities is to enhance the public understanding of what those rights are. More importantly, unless and otherwise children with disabilities and their caretakers are fully aware of their rights to access services and support, they do not claim their rights regardless of the availability of the services and supports.

Graph 16: Awareness of child rights



Encouragingly, a large majority of both child and carer respondents of this study were aware of the four child rights outlined in the graph, with a slightly larger number of carers than children being aware of each right. The gender split between children who didn't know their rights was even, while 29% of those who were unaware of their rights had intellectual disabilities; 29% had hearing disabilities; 26% had physical disabilities; and 17% had visual or multiple disabilities. This bolsters the need for the state, NGO sector and society as a whole to accept and promote the rights of children with disabilities, to ensure that they are not violated. We must also remember that many of the children in the study already had access to CBR programmes and NGO interventions – as such, further analysis is needed to ascertain how aware all children in Ethiopia are of their rights and how this awareness can be raised if necessary.

One key informant, the community leader quoted below, stressed the fact that community members (himself included) were generally unaware of disability policies and that this was a failure of the policy makers, a view shared by all the key informants. The disabled street children who participated in the forum group discussion stated that the government made them feel like 'second rate citizens'.

*"The community does not actively enquire to know about newly adopted government policies. Similarly, policy makers do not exert themselves to introduce new policies to the community".*

**Community leader, key informant, Adama**

The community leader added that NGOs should advocate on behalf of children with disabilities, and that accessibility of services and legal counselling should be sought. Another key informant from Hawassa stated similar convictions: that the community wanted to assist disabled people, but lacked the official support and knowledge and did not know where or how to start the process of helping them demand their rights. Given the common view that the government is not providing enough assistance to children with disabilities, MoLSA and the ministries of health and education must prioritise the funding of policies directed at disabled children, to increase capacity and assistance in this area.

#### **4.3.4 Access to education and learning support**

Children with disabilities are entitled to fully enjoy their right to education. But in reality, the vast majority of children with disabilities in Africa have limited access to education due to various reasons including architectural inaccessibility of schools, lack of well trained special need teachers, lack of accessible transportation or non-adaptation of education materials. As a result, significant proportions of children with disabilities are not enrolled in school at all or are compelled to drop out of school.

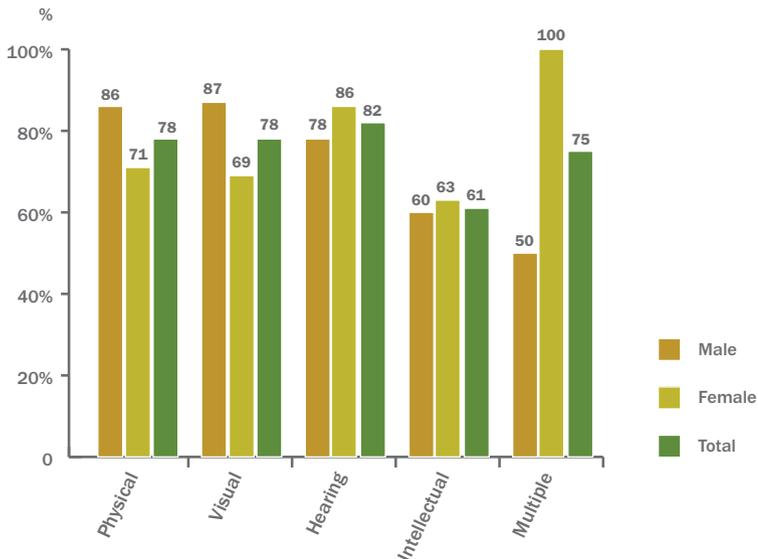
*"I need supportive equipment. I can't go to school because I get tired walking, and need crutches or a wheelchair so that I can continue to learn".*

**Physically disabled girl, 12**

Surprisingly, the majority (76%) of the sample of this study (78% of boys and 73% of girls) was enrolled in school at the time the study was conducted. Boys with multiple (50%) or intellectual (60%) disabilities were least likely to be in school, while boys with physical disabilities and girls with hearing impairments (both 86%) were most likely to be in school. Greater effort is therefore needed to ensure that children with intellectual and multiple disabilities are afforded the same opportunity to learn as other disabled children – at a vocational skills learning centre should their disabilities prevent academic learning. This implies that children with cognitive or learning disabilities face additional stigmas and barriers to education, even among children with disabilities, and requires further analysis.

Of those not in school, 48% had never been to school, and the remaining 52% had previously attended school. The most common reasons for no longer attending school included: the school’s inaccessibility for disabled children (16%); the school actively excluding the child on the grounds of his or her disability (12%); and the child believing that they were unable to learn (10%). Those who had never been to school cited similar reasons: inaccessibility of nearby schools (17%); the lack of a nearby school (13%); carers not wanting them to attend school (11%); and a lack of interest in attending school (9%). Disabled street children stated that the public’s false belief that they were supported by government bursaries meant they did not get help to access education.

Graph 17: School enrolment of child respondents, by gender and disability type



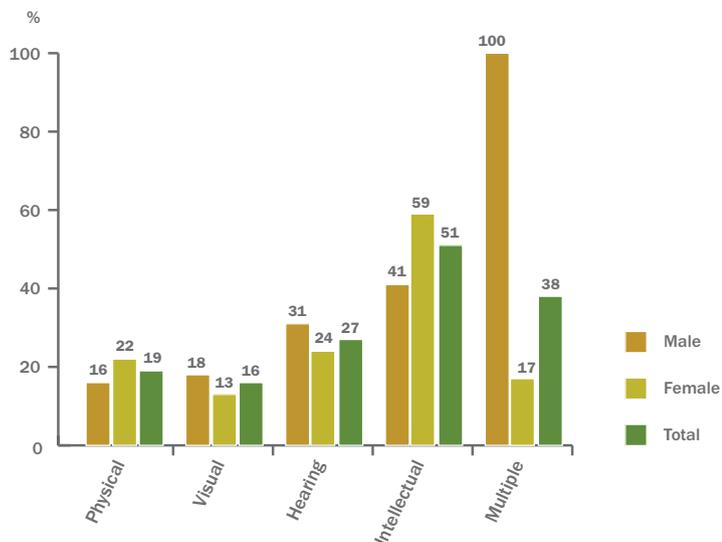
*“There are different factors impacting on my learning. My parents are both dead, so my sister is my primary carer. We have another sister who is also disabled, and our carer sister had to get divorced to support us both. We have no money for clothes, shelter or food”.*

**Visually disabled boy, 13**

When asked about the type of school their disabled child attended, carers answered that 77% attended regular school; 14% attended a special

school; 8% attended remedial special classes in mainstream schools; and less than 1% attended other types of schools. Additionally, 18% had attended a pre-school, crèche or play centre before the age of five, and 19% had been denied access to regular schools at least once (42% of children with multiple disabilities; 29% of those with intellectual disabilities; 19% with hearing impairments; 18% with physical impairments; and 10% with visual disabilities).

Graph 18: Number of child respondents who have had to repeat at least one grade in school, by gender and disability type



According to the children currently enrolled in school, 26% had to repeat at least one grade. Rates ranged from 59% of girls with intellectual disabilities to 14% of girls with visual disabilities. The 100% of boys with multiple disabilities repeating a grade refers to

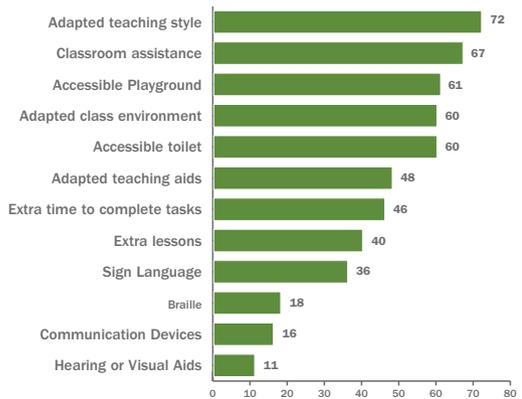
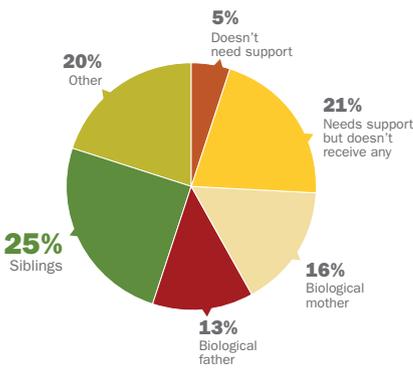
a very low sample of two. The high level of grade repetition, and the number of children not attending school for reasons of accessibility show that even when schools attempt to make their premises physically accessible, they can often still not

guarantee an accessible learning environment for disabled children, who remain less likely to achieve positive learning outcomes than their non-disabled peers.

Sixty per cent of children had missed school for more than two consecutive weeks at least once, for different reasons including illness (33%) and

not having someone to take them to school (11%). To get to school, 85.1% walked; 3.5% used public transport; 1.7% wheelchairs; 1.2% cart or mule; 0.7% each used private transport or a school bus; and 7.5% used “other” modes of transport, including lifts from friends and teachers.

Graph 19: Homework and school support for child respondents (child questionnaire)



With regards to needing support from others to complete their homework, 5% of those enrolled in school did not feel they needed any support; 21% believed they needed support but did not receive any; 29% received support from one of their parents; 25% from a siblings; and 20% from other sources, including teachers and friends. When carers were asked the same question, 3% said they believed the child did

not need support; 17% that the child needed support but did not receive any; 39% that one of the child’s parents helped out; 24% that one of the child’s siblings supported them; and 17% that other individuals assisted the child. To achieve learning outcomes, Inclusive education must include learning assistance, in the form of peer, teacher or carer help where possible.

Picture 2: *Adissu with his school friends*

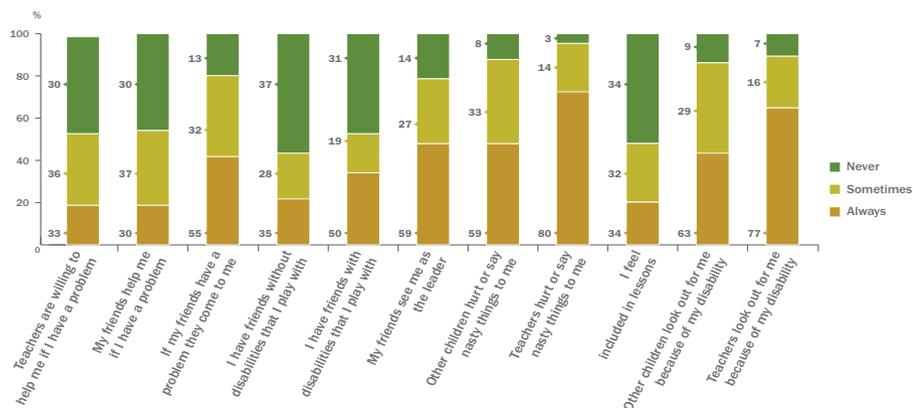


A reassuring majority of the child sample felt that their school had adapted both their learning and play environments in various ways, to facilitate their needs: 72% felt that their teachers had adapted their teaching style to ensure that it was easy for the child to understand; 67% received assistance in class from another child or a classroom assistant; and 60% worked in an adapted class

environment (i.e. with additional lighting or in a space at the front near the board). Less positively, only 60% of school-enrolled respondents had the use of an accessible toilet; and only 61% could access the school's playground.

These results must be taken within the context of knowing that the majority of respondents were enrolled in CBR programmes, and that such a high level of school enrolment is not representative of the country as a whole. However, a focus group discussion conducted with disabled Addis Ababa University students disclosed their belief in an upward trend in inclusive and special needs education in Ethiopia, although they also stressed that further progress is still needed. We believe that, although best practice from inclusive and special needs schools needs to be repeated, these schools must make continued efforts to ensure total physical and learning accessibility.

Graph 20: *Interaction of child respondents with their peers and teachers in school*



When asked about their interactions with their peers and teachers, approximately two-thirds of respondents felt that they had other children to play with always or sometimes – 65% with non-disabled friends and 50% with disabled friends; 66% said that their teachers were supportive of their needs. However, 55% felt that their friends would not come to them with a problem; 59% felt that their friends never saw them as a leader; and 77% believed that their teachers did not look out for them because of their disability specifically. One key informant – an SNE-trained teacher in Bahir Dar – stated that children with visual disabilities appeared to have no problem playing with non-disabled children; that hearing-impaired children were entirely alienated due

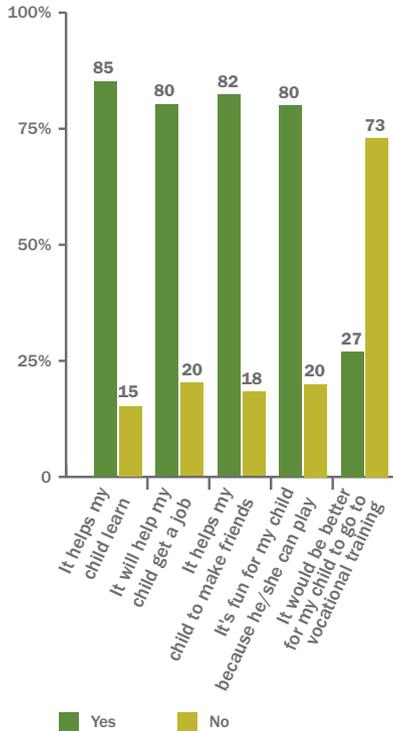
to their incapacity to communicate with others; and that intellectually disabled children were often bullied because of the negative stigmas surrounding their conditions. Again, this implies the need for teachers to ensure a supportive and open learning environment for disabled children, and that physical accessibility alone does not ensure equal opportunity in learning outcomes.

When asked what they wanted to be when they grew up, both boys and girls gave very similar answers; the top five are shown in Table 5. It is worth noting that 4% of girls said they didn't think they would ever get a job, compared with 2% of boys. More boys said they wanted to be an artist, driver, engineer or mechanic than that they would not get a job.

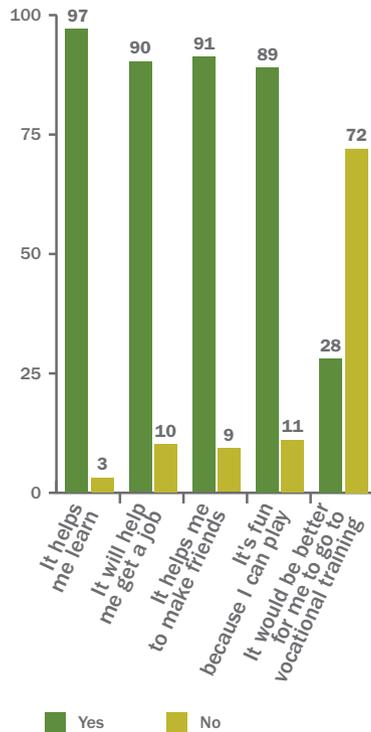
Table 5: Future professions: top five answers from child questionnaires

	Male	Female
1	<b>Doctor</b> (21%)	<b>Teacher</b> (24%)
2	<b>Teacher</b> (19%)	<b>Doctor</b> (22%)
3	<b>Trader/ businessman</b> (9%)	<b>Civil servant</b> (7%)
4	<b>Civil servant</b> (7%)	<b>Trader/ businesswoman</b> (6%)
5	<b>Engineer</b> (4%)	<b>I don't think I will ever have a job</b> (4%)

Graph 21: Carers' perception of their child's school



Graph 22: Child respondents' perceptions of school



One of the six *A day in the life* stories (see Appendix 2), is by a young disabled boy in urban Ethiopia. Despite his disability, he feels included and valued among his friends and family. It is interesting to note that the sport teacher believes he is unable to participate in sport activities, effectively creating a barrier to his participation that would otherwise not exist. Teachers and families of disabled children must learn to listen to the children themselves. If they feel able to participate in a given activity (at school or elsewhere), they should be provided the appropriate means to do so.

*"I want to learn and to help change my country".*

**Intellectually disabled girl, 13**

The children and their carers were asked to give their perception of the usefulness of disabled children attending school. The vast majority of the children who responded – regardless of whether they were currently enrolled in school – were positive about attending school because: it allowed them or would allow them to learn (97%); it helped or would help them find employment (90%); it helped or would help them make friends (91%); and it was or

would be fun because it allowed them to play (89%). However, 28% believed that vocational training would be better for them than school. Similarly, 27% of carers believed it would be better for their children to attend vocational training than school, but were slightly less positive than the children were about the impact of attending school on the child's ability to learn (85%); get a job (80%); make friends (82%); and have fun (80%).

The children almost unanimously believed that their education would help them get jobs and live independently, illustrating the strong will and determination of disabled children in Ethiopia to integrate fully in economic and social life. It is important to publicise these results to encourage schools and communities to increase their understanding of equal abilities and deserved equal opportunities for all children, regardless of their disability.

One key informant – a teacher at an inclusive school in Addis Ababa – told interviewers about his personal experience of disabled children who wanted to attend school, but were forbidden from doing so by their families, who feared insults or abuse would be directed at themselves or at their children. He praised the disabled children in his classes, stating that they were bright and eager to learn, and that they socialised well with the non-disabled students. However, he criticised the new government schools that are currently being built in the city, which have five steps up to the entrance and no ramp as a building standard, in contradiction to the Ethiopian SNE strategy and UNCRPD.

Another key informant – a teacher in Adama – also mentioned that, after approaching the families of disabled children to ask why they were not in school, he had been told that the parents feared social stigma; some even said they believed their disabled children to be 'useless' or 'hopeless'. This teacher also pointed out the presence of other teachers who are unaware of the presence of hearing-impaired children in their classes, or who did not know how to assist them.

The key informant from Adama also gave an example of good practice, saying that their school taught disabled children life skills, including cookery classes, where they cooked food for other members of the school community. He also said that the school provides special classes for children with intellectual, hearing and visual disabilities, but only until Grade 5:

*"This shows that children with disabilities have the capacity to do whatever it is that other normal people can do if we give them the opportunity to learn... However, in the absence of conducive environment for education after Grade 5, most of them are forced to abandon their education. So, we can say that the education given to children with disabilities is not sustainable and cannot secure their future economic and employment opportunity".*

**(Key informant: teacher from Adama)**

Only one of the key informant teachers was aware of, and had been trained in, the national SNE strategy. This teacher from Bahir Dar worked at another inclusive school that only provided education for children with disabilities until Grade 5. She felt that the demand for SNE training was far greater than the supply, and that

many disabled children in the locality attended schools where no teachers had received SNE training, and were therefore not capable of providing them with appropriate and effective learning. She stressed the need for further research on the education of children with intellectual disabilities, as she felt this was the area that her SNE training had not prepared her for.

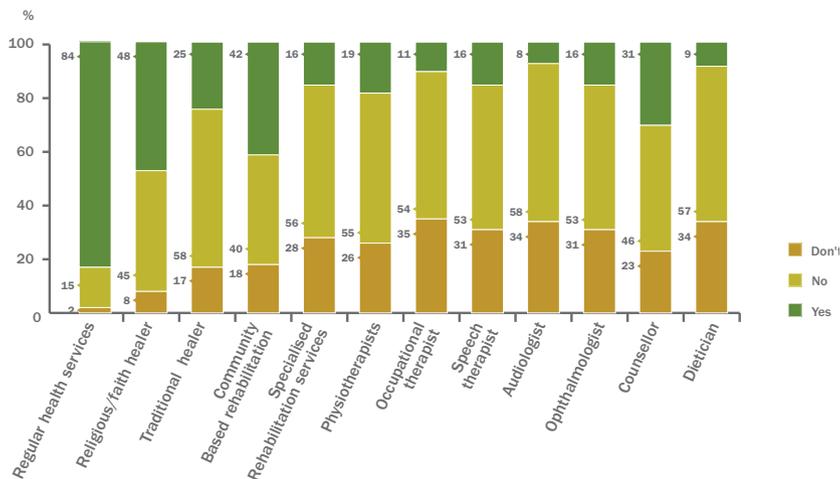
### 4.3.5 Access to health care and wellbeing

Access to health care is generally difficult in most African countries, but the problem is even worse for children with disabilities. To begin with, due to the prevailing attitude

towards disability, many parents hide their children with disabilities denying their right to access the limited available health care services. Lack of awareness on available specialized health care, physical as well as attitudinal barriers to access such services; and legislative and administrative barriers make health care services inaccessible by children with disabilities and their carers.

When asked about the availability of a number of health care services to their community, 84% of carers said they were aware of regular or primary health services in their area; a worryingly high 15% said that there were no such services in their community.

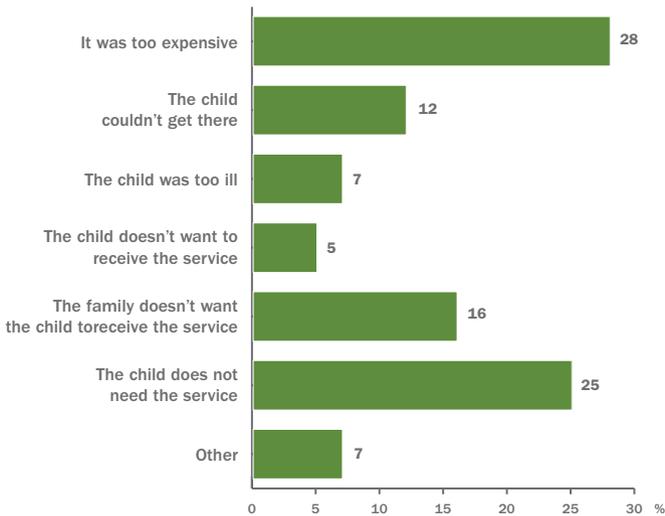
Graph 23: Types of health service available to disabled children in their community (carer questionnaire)



A good proportion of carers knew of CBR programmes (42%) and counsellors (31%) in their communities. However, not many knew about other services available – physiotherapists (19%);

occupational therapists (11%); speech therapists (16%); audiologists (8%); ophthalmologists (16%); and dieticians (9%). The majority did not know whether the services existed or not.

Graph 24: Reasons disabled children do not use available known health services (carer questionnaire)



Of the carers who knew about the various health services, 69% used them to assist in the treatment of the disabled child under their care. The main reasons cited for not using the services (by those who were aware of them) were: too expensive (28%); the child did not need the service (25%); the family did not want the child to receive the service (16%); and a lack of accessible transport (12%).

As we discussed in 4.1.2, 35% of the child respondents were born with a disability. Many of these may have been the result of malnutrition or under-nutrition, prenatal diseases among the mothers or poor sanitary conditions. This indicates that a lack of basic health care services and low standards of living could be linked to the prevalence of disability in Ethiopia (see 4.2.2).

Picture 3: Adissu attaches his prosthetic leg



Disturbingly, 12% of respondents said they could not afford to access primary health care services, while physical inaccessibility prevented an additional 2% from accessing them. Out of those who knew of religious or traditional healers in their communities, a relatively large number (29% and 55% respectively) said they did not want the child to receive that service. This shows a positive move forward from traditional stigmas and the view that disability is a curse that can be cured through faith.

*“We tried to cure his injury with traditional medicine, but now we want to take him to a big hospital”.*

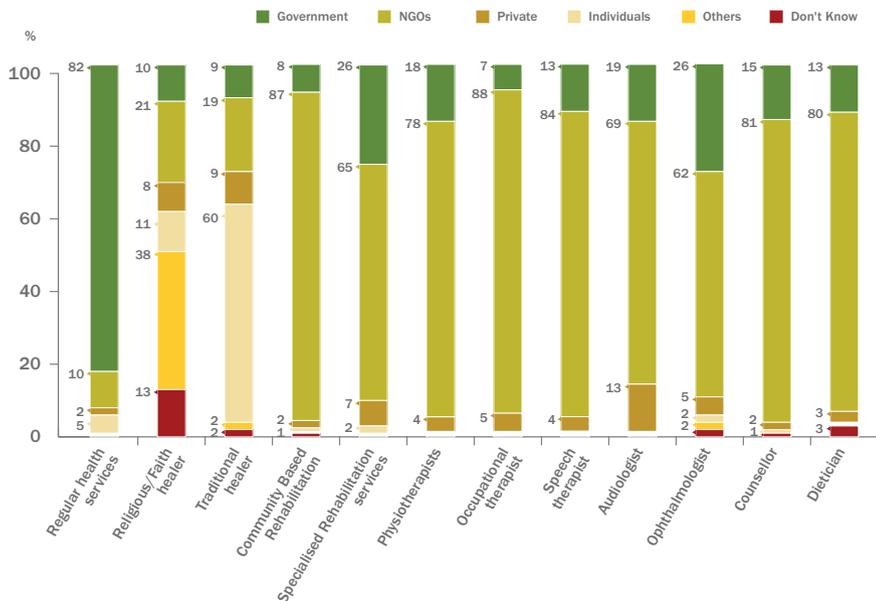
**Carer of a physically disabled boy**

Disabled street children who took part in the focus group discussion stressed

that they knew about their right to free primary health care but could not provide the permanent residency identification required by kebele officials to register them. They criticised the fact that no one had facilitated this, or given them information on how to access health care and education.

The government provided 82% of regular health services, 26% of specialised rehabilitation services and 26% of ophthalmologist services. NGOs provided the vast majority of other health care services, including 87% of CBR services; 65% of speech therapy; 84% of occupational therapist services; 88% of occupational therapist services; 69% of audiologist services; 62% of ophthalmologist services; 81% of counselling services; and 80% of dietician services.

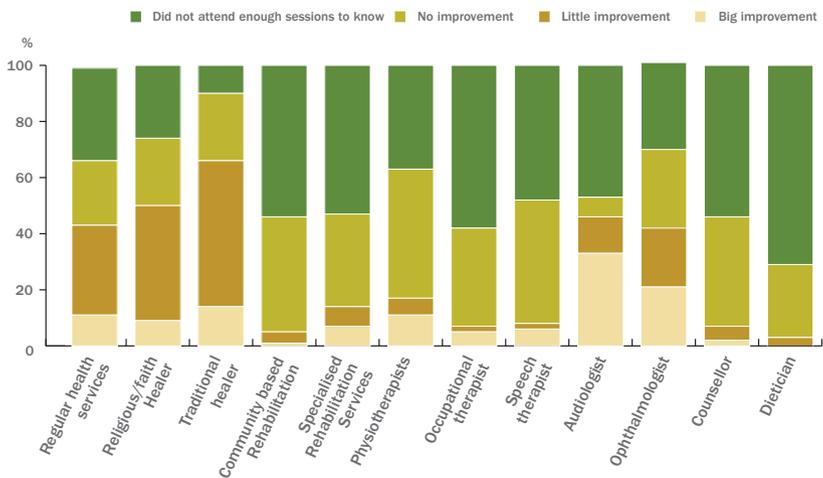
Graph 25: Health service providers [currently available to child respondents]



Users of regular health services, the majority of which were provided by the government, reported low benefits, with 11% saying they did not have enough access to the service to know whether it was helpful; 32% reporting no improvement; and 22% seeing a small improvement. The majority of those using religious and faith healers

also reported low or no improvement, but encouragingly, many of those using NGO-provided services reported big improvements. NGO services used were: CBR (54%); specialised rehabilitation services (53%); occupational therapists (58%); speech therapists (48%); seeing counsellors (54%); and dieticians (71%).

Graph 26: Improvements seen by carers after using healthcare services, by type (carer questionnaire)



A key informant (Health Worker) from Adama stated that in his personal experience, the condition of children with medical diagnoses often deteriorated when they were not taught –or reminded – about best practice in caring for and minimising their impairments. This highlights the need for disabled children to be actively involved in their own treatment and rehabilitation, so they can take ownership from an early age.

*“When we give birth, the children often get sick with something that can be cured easily, but when left untreated becomes a disability. We need better access to health institutions”.*

**Carer of a physically disabled boy**

Another key informant – a community leader in Adama – believed that the city’s health facilities were insufficient for all members of the community, and disabled people in particular. He also acknowledged efforts being made by other stakeholders by mentioning a programme that a local disability NGO

introduced in the *iddir* (community savings association) to educate orphans and vulnerable children (including those with disabilities) on their medical and legal rights, and to educate the *iddir* members on the general rights of disabled children.

A health care worker in Addis stressed the need for health care professionals to be better trained in diagnosing and treating intellectual disabilities. He believed this to be the least visible and least understood childhood disability, which consequently suffers the lowest standards of care. Nevertheless, he praised DPOs such as ENAID and ENAD for raising awareness about, and combating stigma against, childhood disabilities.

Encouragingly, health care workers interviewed in Adama and Hawassa said they were aware that all persons – with and without disabilities – were entitled to free services in government hospitals, provided they showed papers of destitution which is an official proof

from local administration that they are poor.

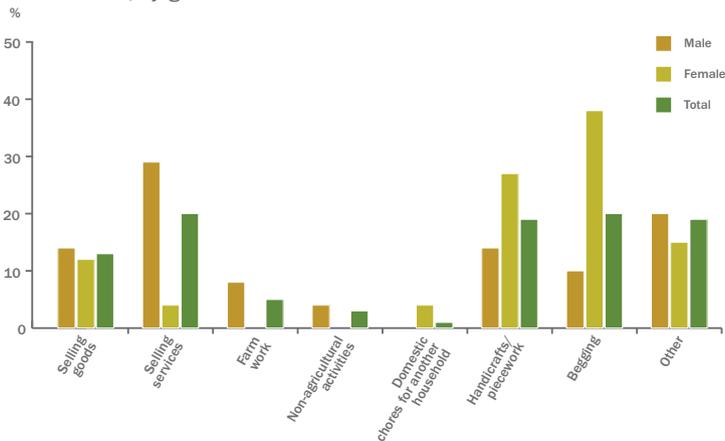
### 4.3.6 Access to work

Due to the resultant cost of having a child with disability in the household and the limited support such households receive from outside the family, children with disabilities are sometimes compelled to work for money, goods and favours in order to contribute to the welfare of the household. Among the child respondents of this study, seventeen per cent stated that they worked – either in or outside of the house – for money, goods or favours. This is significantly lower than the 50% of children aged 5 to 14 involved in child economic activity cited by the World Bank’s 2007 study of child labour and youth employment in Ethiopia (Guarcello and Rosati 2007).

*“You want to know about my problems? I have many. When I work I fall, and when I stand, I need help”.*

#### Physically disabled girl, 15

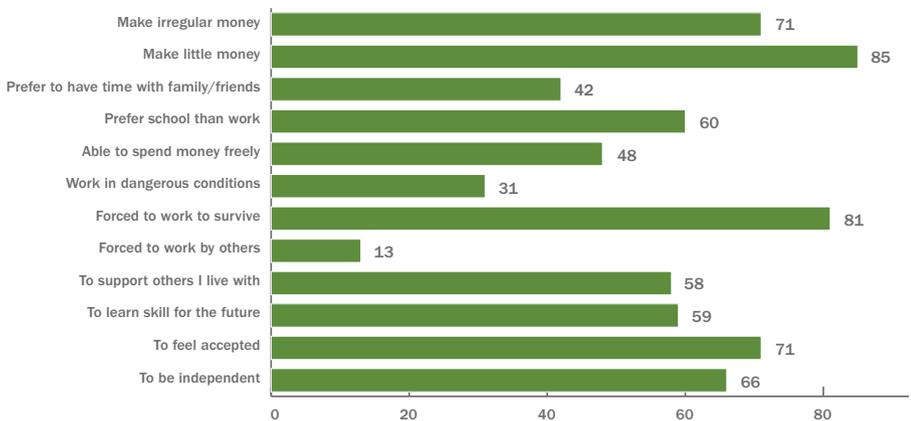
Graph 27: Type of work done by child respondents who work for money, goods or favours, by gender



The majority of children who worked reported that doing so helped them to: be independent (66%); feel accepted (71%); learn skills for the future (59%); and support others (58%). Few (13%) were forced to work by other people, while the majority (81%) felt compelled to work to survive. Approximately a third (31%) – mostly children who begged or sold goods by the road – considered their working conditions to be dangerous, but a large majority (85%) felt that they made little money

in relation to their work hours, while 71% said that their income was irregular. Finally, nearly half of the children were content to work rather than attend school (40%) or spend time with friends and family (58%). This figure shows that a large number of working disabled children believe this to be the right option for them, but it is impossible to tell from the data whether this is a consequence of the child being denied education and family time, or the child's free will in a nurturing environment.

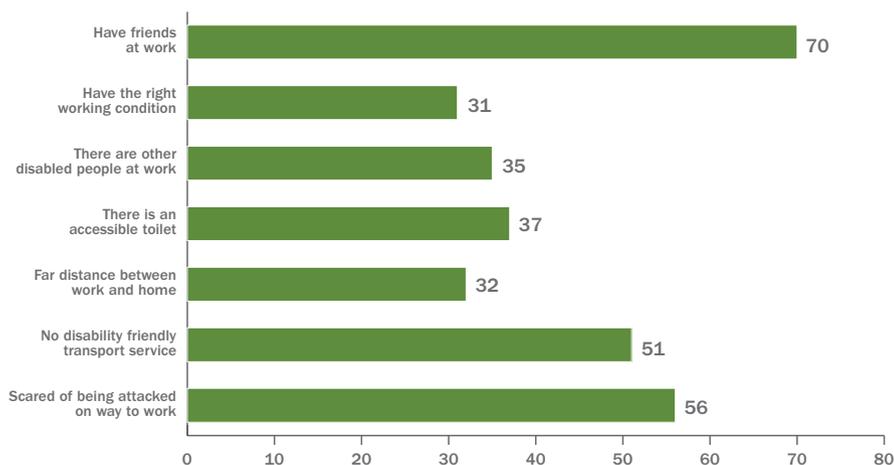
Graph 28: Working child perceptions of their work



Excluding those who were engaged in begging, the children were asked further questions about working conditions and their experiences getting to and from work. The majority (69%) reported that they did not have the right conditions to do

their work; 63% had no access to a toilet and 56% were worried about their safety en route to work. The latter figure suggests that many disabled children experience negative social attitudes that hinder them from equal access to and participation in employment.

Graph 29: Workplace conditions and experiences travelling to and from work (child questionnaire)



### 4.3.7 Access to financial and emotional support

Seventy-seven per cent of carers said that in an average month, their household/institution’s income was not enough to cover the basic needs (including food, shelter and clothing) of the people they lived with – including the disabled child under their care. This was slightly higher in rural areas (80%) than urban ones (74%), and much higher for conventional households (81%) than institutions (24%). Table 6 shows respondents’ main sources of household income.

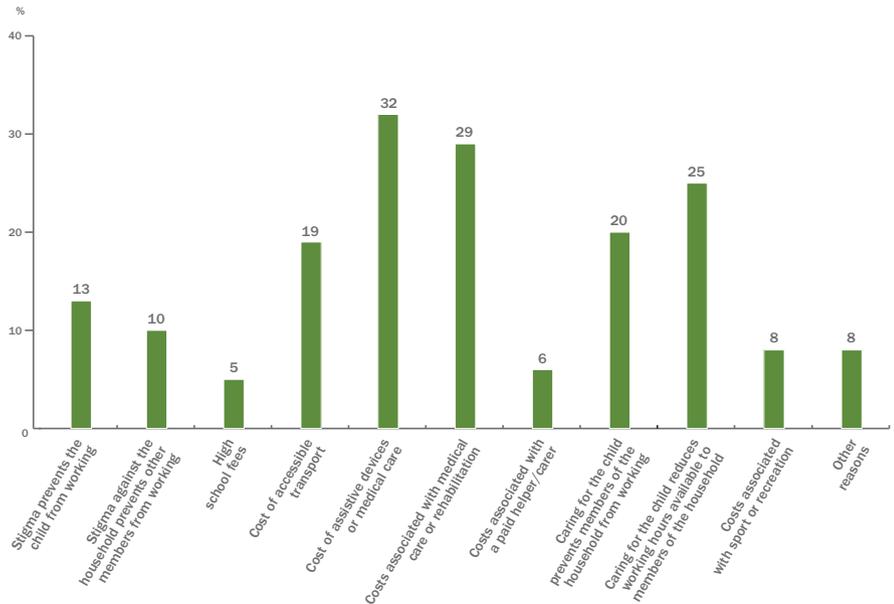
Table 6: Main income source for respondents’ households

	Conventional households	Institutions
Prevalent sources of main income	Subsistence farming (21%)	Donations (52%)
	Wage/salary work (19%)	State grants (12%)
	Informal business (18%)	Wage/salary work (6%)
	No income from any source (5%)	

*“My father does not support any of the children in the household. My mother supports us all and does not have enough money to look after my additional needs”.*

**Physically disabled boy, 13**

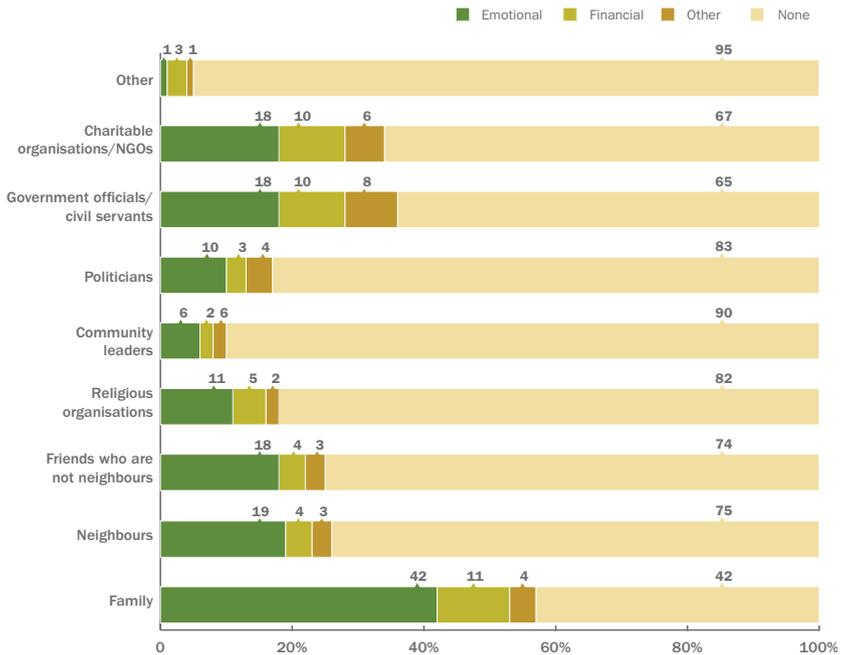
Graph 30: Financial impact of child's disability on the household (carer questionnaire)



Carers were asked about the financial impact their child's disability had on the household. The most commonly perceived financial burdens were the cost of medical care and assistive devices (cited by 32%) and rehabilitation costs (26%). More than a quarter (26%) also reported that household members had reduced their working hours to support the child, which had affected their financial situation.

Financial impacts were mainly consistent across disability groups, with several exceptions: of those who felt burdened by high school fees, almost half (43%) were carers of children with hearing difficulties; more carers of physically (26%) and intellectually (27%) impaired children felt unable to work as a result of having to care for the disabled child under their care, compared with carers of children with visual (18%), hearing (19%) and multiple (9%) disabilities.

Graph 31: Support received by carers in the last 12 months (carer questionnaire)



A quarter of the carer sample had not received any support – emotional, financial or otherwise – from anyone in the 12 months preceding the interview. Nearly half (42%) had received emotional support from their family, while 18% had received emotional support from NGOs, charitable organisations and government officials or civil servants. Very few carers received any financial support, with 11% receiving financial assistance from family, 10% from the government or charitable organisations, 5% from religious organisations and 4% from neighbours or friends.

When asked about the support they got from their carers, 40% of children reported that they never made their own decisions, 20% got no support in achieving their goals; 21% got no support to undertake difficult activities; 37% had no financial support; 20% had no emotional support. The majority indicated that they did not get much support from the wider community: 60% never had anyone to go to for emotional support; 75% had nobody to approach for financial support and 58% never got help with activities they found difficult.

## 4.4 Social integration

Social integration of children with disabilities begins in the family. However, all efforts of the household should further be enhanced by the wider community in order to ensure the full inclusion and participation of the children in all aspects of life. Therefore, the extent to which children with disabilities participate in family as well as in community activities can be taken as good indicators of their integration.

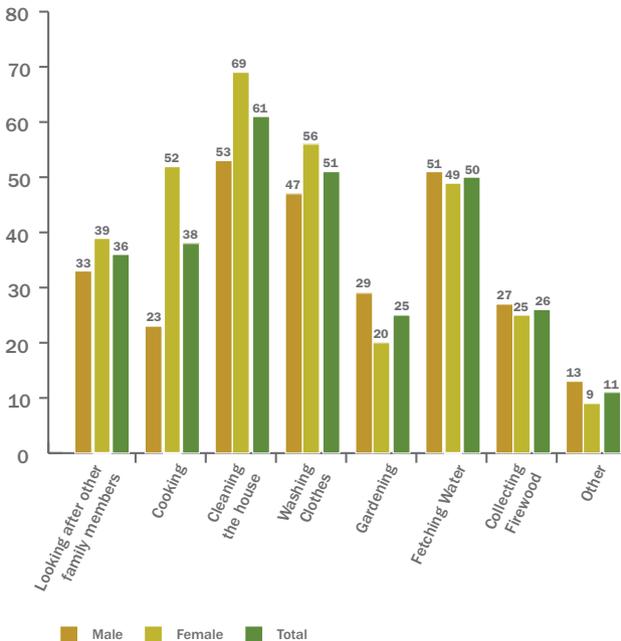
### 4.4.1 Participation in family

The majority of the children – 74% of

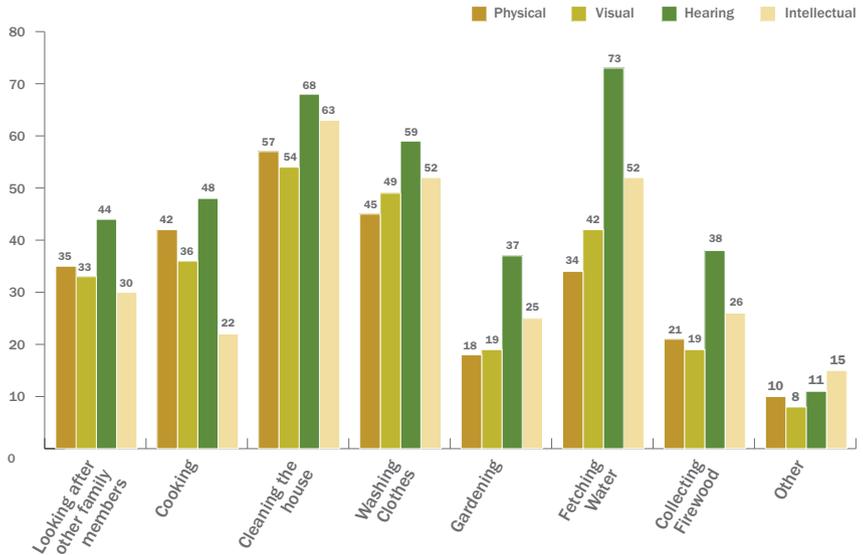
girls and 67% of boys – stated that they helped with household chores. Children with hearing disabilities were most likely to do chores (77%), followed by children with intellectual disabilities (70%), visual (69%) and physical disabilities (66%).

Those who did not participate in household chores cited various reasons including: inability due to disability (43%); a refusal to participate (21%); a lack of will by the child’s carer to allow them to participate (11%); the fact that there is a housemaid to do the chores (10%); and others, including being considered too young (15%).

Graph 32: Chores undertaken by child respondents, by gender (child questionnaire)



Graph 33: Chores undertaken by child respondents, by disability type (child questionnaire)



The most common chores the children did were: cleaning the house (61%); washing clothes (51%); and fetching water (50%). With the exception of cooking (52% of girls and 23% of boys), there was little gender differentiation. There was quite significant differentiation however, between disability types. Children with intellectual disabilities were much less likely to perform certain tasks, such as looking after other members of the family (30%) or cooking (22%), and more likely to do the washing (52%) or fetch water (52%). A surprisingly high number of children with visual disabilities were involved in fetching water (42%), cooking (36%) and collecting firewood (19%).

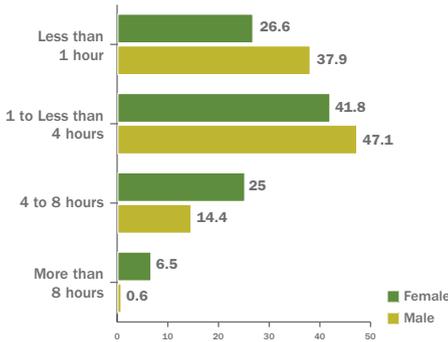
Picture 4: Getachew and his sister fetching water, one of his chores



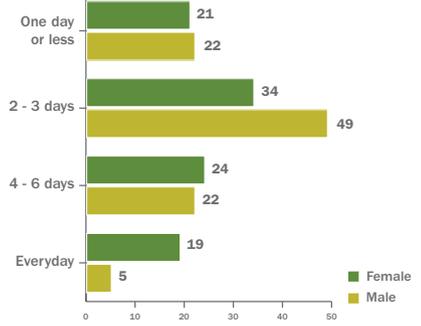
Of those who did chores around the house, 45% worked between one and four hours a day, 32% worked for less than one hour, 20% worked between

four and eight hours, and less than 4% worked more than eight hours. Girls were more likely to work more than four hours than boys, and also more likely to work most or every day.

Graph 34: Hours a day spent doing chores (child questionnaire)



Graph 35: Days a week spent on chores (child questionnaire)



Picture 5: Adissu helping prepare akenbalo, the family's only source of income

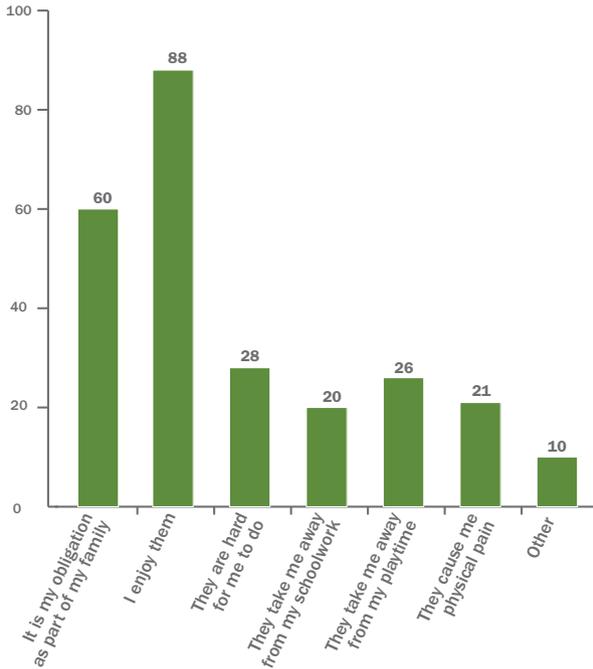


Asked how they felt about their chores, 88% of the children said that they enjoyed them, and 60% felt that it was their obligation as part of their family. A smaller number thought their chores were hard (28%), that they took away time for school work (20%) and play (26%), or caused them physical pain (21%). Carers' responses were almost identical: 87% said the child enjoyed performing their chores; 65% said it as the child's obligation; 57% said the chores took the child away from activities he or she enjoyed; and 21% that they caused the child physical pain. The enjoyment many children found in their chores exemplifies the positive emotional ramifications of familial inclusion, even when the child finds the chore itself unpleasant. While this is encouraging, given that

assisting the family is an inherent aspect of Ethiopian society, 24% of the children did chores for their household for more than four hours a day. There is no data on the time non-disabled

children in similar socio-economic settings spend doing chores, but this is a long time, especially when the chores cause physical pain and reduce the time available for school work and play.

Graph 36: Child respondents' perception of their chores



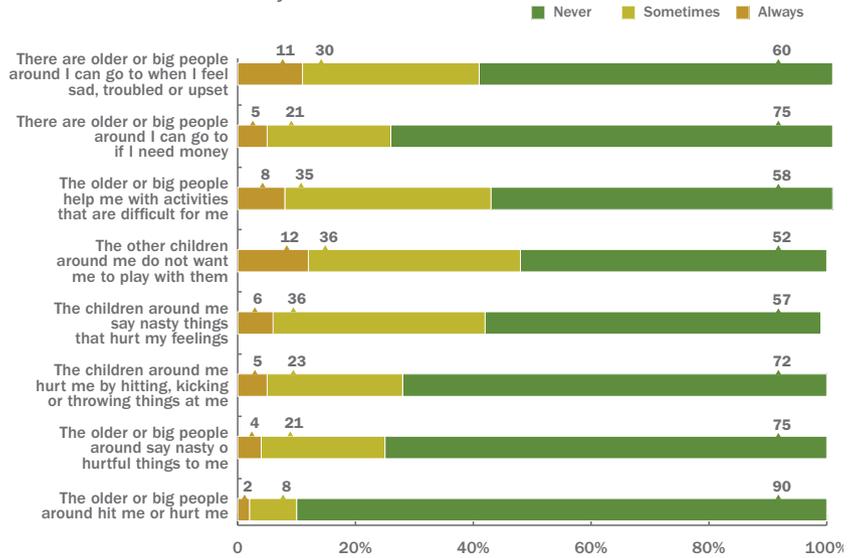
A considerable number of children felt isolated from: social or family time (13% always and 32% sometimes); important household decisions (17% always, 37% sometimes); religious gatherings (16% always, 24% sometimes); and family events and social gatherings (16% always and 29% sometimes).

On the other hand, most carers believed that the children were involved

in the majority of household activities. However, a minority indicated that they suffered exclusion themselves as a result of being the primary carer of a disabled child, with 6% excluded from family gatherings and social events, 3% verbally or physically abused by household members, 6% verbally or physically abused by members of the community and 4% excluded from family time.

#### 4.4.2 Participation in community life

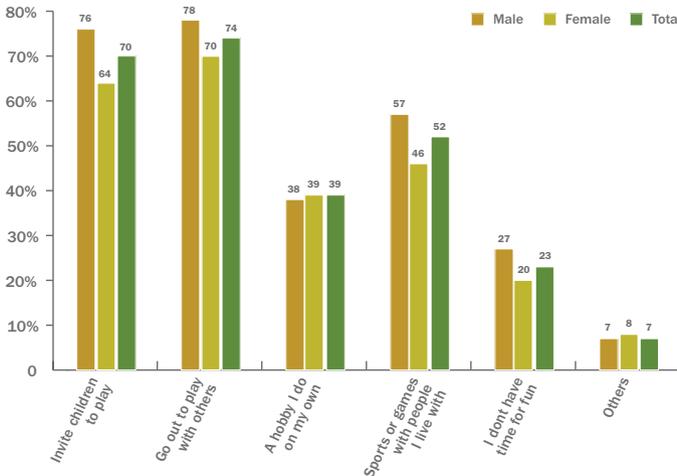
Graph 37: Disabled children's standing in the community and relationships with other community members



More children were victims to verbal abuse (28%) than physical (18%). Although the majority of children were not actively abused by those around them, a sizeable minority (6%) were

abused either 'sometimes' or 'always'. Sadly, a small minority (4%) were 'always' on the receiving end of verbal or physical abuse from children and/or adults.

Graph 38: Favoured recreation activities



When asked what activities they liked to do for fun, 70% said they invited other children to play at their house, while 74% went out to play with others; 39% liked to do a hobby by themselves; and 52% enjoyed sports. Sadly, 23% didn't feel that they had time for fun: this is an issue which needs further examination, given the inherent importance of play in early childhood development and a child's emotional wellbeing. Of those who said they had no time for fun, 85% lived in conventional settings, 10% in institutions and 4% on the streets. By disability type, 35% of those with no time for fun were children with physical disabilities, 25% had hearing disabilities, 22% visual disabilities and 15% intellectual disabilities.

The children were asked if they had any comments about their life as a disabled child. Fifty children mentioned a need for better education and support, while a further 20 stated that they needed access to an inclusive school and accessible equipment. Twenty six children affirmed their need for medical support, and 10 talked of their desire for psychological support. Despite their young age, an impressive 19 children stressed the need for the appropriate implementation of legal instruments. Others mentioned the need: for assistive devices; to engage in income-generating activities

and vocational training; to improve the community's attitude towards disability; and to increase accessibility in their community.

*"I don't know how my life will improve in the future, but if I get the opportunity, I want to be a doctor and improve my life. God will help me".*

**Visually disabled girl, 9**

Carers were asked the one thing they thought would improve the life of the disabled child under their care, and whether they had any final comments. Answers to these two questions overlapped, with over half of all carers mentioning the need for education; both inclusive and special schools; SNE-trained teachers; or assistive school equipment. In addition, 18.1% of carers asked the research team and other affiliated NGOs for financial support; about 20% stated the need for medical and psychological assistance or assistive devices such as hearing aids and crutches. Finally, carers mentioned the need for: income-generating activities; care and support from the community; vocational training for their child; holy water treatment for their child; raising awareness [of disability issues in the community]; and recreational facilities.

Quotes from the children and their carers, taken from answers to these questions, are included throughout this document.



## 5. Commentary

### 5.1 Education

The large percent (76%) of child respondents enrolled in education was uplifting, but unlikely to be representative of the country situation as a whole. Key informants and open-ended responses by both carers and children stressed prevailing stigmas and the lack of inclusive schooling past a specific age (often Grade 5). There needs to be further research to investigate why this is so, and whether all disabled children in Ethiopia have the same level of access to education as those in the sample.

There is also a need for Ethiopia's SNE strategy, the ESDP and TVET programmes to be scrutinised to ensure adequate regulations with respect to disabled children, both on paper and in practice. It is clear from our research that disabled children need more support – from their carers, teachers and school administration systems – to ensure they have full access to an appropriate learning environment.

### 5.2 Health care

The lack of birth registration and the alarming 55% of respondents who are using regular primary health care services with little or no improvement in health both point to a major problem in the prevention and treatment of disability in Ethiopia. It is quite plausible to link inadequate primary health care – including the lack of immunisation and emergency treatment – with the

high incidence of illness-induced disability. This must be addressed in the upcoming MoLSA national plan for the physical rehabilitation sector in Ethiopia (currently in draft form).

More encouraging is the fact that users of CBR programmes and speech or occupational therapists (services that are predominantly run by NGOs) were on the whole satisfied with the results. This indicates the meaningful role that NGOs are playing, and must continue to play, in improving the lives of disabled children in Ethiopia.

### 5.3 Poverty and wellbeing

A disturbingly high number of carers stated that they were unable to meet their household's basic needs (food, shelter and clothing) on an average month. Many felt that caring for a disabled child meant they faced significant additional costs. This stresses the need for better financial and emotional support mechanisms for carers – 25% received no support at all in the 12 months prior to the survey; the majority of those who did received emotional support only.

While it is worrying that so many of the respondents lived in material poverty with limited access to basic services, it was elevating to find that most child respondents had positive expectations of the future and their ability to live an equal life to others in society. Many had aspirations of well-paid and respected positions, and believed in

their capacity to have a family of their own and to support their carers.

#### 5.4 Family participation

While only a minority felt that their carers beat or verbally abused them because of their disability, the feeling of exclusion from family and social events and decisions was widespread. Consequently it would appear that while most carers did not physically or verbally harm their child, they (unintentionally or otherwise) emotionally abused the disabled children under their care by excluding them from family events and decisions or preventing them from going to school. A much smaller percentage of carers felt that they too were excluded from family events and decisions as a result of the disabled child under their care. These experiences highlight the urgent need for community education on disability and related stigmas.

#### 5.5 Employment

Of the 17% who worked, a large majority felt they had to do so to survive, highlighting negligence on the part of the government in its requirements under the UNCRC to protect all vulnerable children from exploitation. All the children who worked did so in the informal sector, often in exploitative situations which were potentially dangerous, poorly paid and lacked appropriate support. This was particularly so for those involved in begging, running errands or carrying out domestic chores for

other households. It is vital that the government address this issue, as well as the lack of opportunities for disabled children to enter vocational training and the fact that inadequate inclusive and SNE leads to a low rate of academic success and consequent job opportunities among disabled children.

*“In the end, we all wish to see a better future for children with disabilities”.*

**Carer of an intellectually disabled boy**

#### 5.6 Social barriers and community support

The quantitative and qualitative tools produced conflicting evidence on community participation, making it clear that some communities are more inclusive than others. A sizable minority of child respondents stated that they had been verbally or physically abused by other community members (both adults and children), and the majority did not feel they could approach anyone in their neighbourhood for emotional (60%), financial (75%) or physical (58%) support.

Some carers are clearly fatigued by consistent NGO and other public service providers promises to solve issues and problems faced by disabled children in Ethiopia and their carers. This highlights the futility of poorly planned interventions, and points to the urgent need for suitable and sustainable solutions to these problems. Moreover, it underlines the need for researchers to conduct valid surveys that will highlight the issues

in a language that policy makers understand. It is also vital to identify and showcase the best practices of NGOs working in disability, and then replicate and extend these to all regions.

*“Different institutions and individuals have not brought about the desired change to disabled children so you [researchers] better keep your promise and find a worthwhile solution”.*

**Carer of a boy with multiple disabilities**



## 6. Recommendations

### 6.1 Education

*The bottom line of inclusive education, is how it meets the developmental and social needs of children with disabilities.*

Tirussew 2006 p 65

- *The government must ensure there is sufficient budget for the SNE strategy: Measures have been taken, on paper at least, to include children with disabilities in Ethiopia's ESDP III. However, our survey results and secondary sources have revealed that, although more disabled children from our sample are in school than we expected, inclusive education in Ethiopia remains fundamentally inadequate. Significant increases in resources are necessary, to train the appropriate number of teachers in SNE, and to better equip educational units with accessible learning materials and facilities. A better monitoring and accountability system is also required – at regional, woreda and school levels – to ensure that the special needs of disabled children are incorporated into budgets and strategies at each level, and that drop out/repeat rates are examined and improved. Regional bureaus of education must be given the necessary budget to adequately implement Ethiopia's SNE strategy, making sure that schools are able and prepared to accept and physically accommodate the needs of disabled children.*

In addition, the best practices from inclusive schools should

be identified, showcased and disseminated to encourage other schools to practice inclusion.

*“All disabled children at every single house should be located and given the opportunity to learn”.*

**Carer of a deaf boy**

- *There must be more efforts to teach sign language to children with hearing impairments, their teachers and families: Ethiopian sign language is thought to have originated from American and Nordic sign languages, but many signs were modified to fit Ethiopian culture (Hailu 2010). Sign language usage promotes self-identity and allows deaf or hearing-impaired children to participate fully in family, social and educational life. Almost 70% of the hearing-impaired children in the sample required sign language interpretation, suggesting that the remainder were either able to communicate verbally, or via an unofficial sign language established with their carer. Greater efforts must be made by all stakeholders to teach Ethiopian sign language to deaf children, their teachers and families, to enable more complete interaction between the children and those around them.*

*“It would be good if teachers learnt sign language, especially if the rest of the community learnt too, so that we could all communicate together”.*

**Deaf girl, 16**

- *There must be more positive reinforcement for disabled children in school:* Seventeen per cent of the child respondents were involved in paid work. It was surprising that many of them did not see their work as taking them away from a viable education. This is possibly a consequence of a lack of positive reinforcement to go to or remain in school and/or of poor learning experiences. There is an urgent need for education authorities at all levels to monitor school enrolment and educational attainment among children with disabilities in Ethiopia, to ensure that they provide adequate learning and other supports.
- *There must be more education for carers and communities on disability-related issues:* Education about disability for carers and society in general, is imperative to ensure access to education for all disabled children in Ethiopia. Some of the NGOs working in the country already practice numerous effective methods to explain disability to parents and communities in a way that increases awareness and understanding about the causes of disabilities, and promotes acceptance and inclusion of disabled children, youth and adults. These include organising awareness-raising meetings of parents through traditional cultural institutions such as coffee ceremonies, *eqqub* (social saving schemes) and *mahber* (community associations), as well as using the radio and TV. Traditional

social mediators – such as priests and imams, teachers and social workers –

can also play pivotal roles in this task, educating families and discouraging negative attitudes and outdated ideas about disability.

## 6.2 Health care

- *Health care services must be physically and financially accessible:* Almost 30% of carers in the survey knew of health care services that would be beneficial to the disabled child under their care, but did not use them due to financial constraints. All health care facilities should be physically and financially accessible to all, with information available in adapted formats, such as braille and through sign language qualified health professionals. Moreover, the government policy of providing free health care to the destitute should be extended to include those whose income levels are affected by having a child or other family member with a disability.
- *Health care service delivery must be improved:* Many health care service users were dissatisfied with the usefulness and impact of the service on their disabled child. There needs to be further research on this issue, to identify whether carers have unrealistic expectations from health care services or whether the delivery of these services is failing those who need them most. There must also be an effective early childhood development monitoring system, which could provide information on the dynamics of disability and primary health care service delivery in Ethiopia.
- *Prevent childhood disabilities:* More

than one-in-three respondents contracted their impairments through illness. Although Ethiopia has taken impressive steps forward in the eradication of diseases such as polio, much still remains to be done to vaccinate and/or treat children against disability-causing illnesses and diseases such as glaucoma, malaria, measles, meningitis and trachoma. The health system needs to make greater efforts to prevent disability through illness and accident, by expanding vaccination and health care awareness-raising activities. Universal birth registration, in line with the UNCRC (Article 7), would also offer protection to disabled children.

- *Promote water, sanitation and hygiene awareness:* Some 15% of respondents did not have access to any sort of toilet facility, prompting concern over the sanitation levels of their households and the possible correlation between families' lack of adequate sanitation and the onset of childhood disabilities. Water, sanitation and hygiene efforts should ensure that educational information on sanitary best practice includes reference to the fact that some impairments can be caused by poor sanitary and hygiene conditions.

### 6.3 Poverty and disability

- *Greater focus on the links between poverty and disability:* Carers consistently said that the costs of a disabled child (medical and rehabilitative costs, as well as lost earnings) created hardship in their households. It is important to make

clear these links between disability and poverty.

- *More information is required:* The government and NGOs should work together to ensure that appropriate and significant statistical research is undertaken to better understand the relationship and impact of poverty on disability and vice versa. Such information would enable the government to design policies and systems to support families with a disabled family member and ensure disabled children can access health care, education and social services.

### 6.4 Employment

- *Better working conditions:* The majority of working disabled children find the income they receive unfair and the working conditions unhealthy. This, along with the fact that 13% of those who worked said that they were actively forced to do so by another person, suggests that disabled minors are being exploited. This situation requires urgent investigation to protect children from exploitation. While the priority should be to remove children from such situations and enrol them in school, working conditions in the informal sector must also be improved for those children who choose to work rather than go to school.

*“As a disabled child I want to work as much as I can to help my community be free from the problems that I have faced. Plus, I want to raise awareness about children with disabilities”.*

**Physically disabled boy, 16**

- *Vocational skills training:* Almost 30% of child respondents indicated that they would prefer to be in a vocational training centre than a school. All public and private vocational training centres should be made inclusive centres, to equip disabled youth with the skills they need to gain sustainable employment. In addition, disabled children and youth should have the opportunity to stay at school and graduate from Grade 10 – a prerequisite for admission to TVET courses. The ministry of education should increase its efforts to introduce SNE in TVET, to provide for the inclusion of disabled trainees in TVET colleges.
- *Equal employment opportunity:* The government should encourage and facilitate job opportunities for disabled youth by enforcing the Proclamation on the Right to Employment of Persons with Disability (no 568/2008) and making all public buildings, transport and communications accessible.

## 6.5 Community support

- *Sustained advocacy to overcome social barriers to participation:* The survey data has shown the many social barriers that prevent disabled children from interacting on an equal level with their families, peers and communities. More importantly, it has shown the desire of disabled

children to have the same opportunities as their peers, and the frustration they experience from their carers' mistaken belief that they are incapable of participation. Sustained and effective advocacy is crucial to ensure that society accepts the capabilities of disabled children, listens to the children themselves and provides equal opportunities to learn, work and participate. This should include awareness-raising at community, regional and national levels, targeting children in schools, teachers during training and all people attending community events, mosque and church services and other public activities.

- *Support for carers:* Very few parents and carers receive any financial or emotional support, and often end up ostracised in their care for the disabled child. Government, the private sector, NGOs and civil society organisations should make support to carers a primary concern, so they can provide for their child. Parents should never be put into the position this mother of an intellectually disabled girl in SNNPR found herself in: "We do not have the capacity to help her; we need her to go and live in an institution".

*"Financial support from foreign sources is not sustainable. It is better for the community to engage children with disabilities in income-generating activities, to show their partnership with the children".*

**Carer of an intellectually disabled boy**

## 7. A Final Note

Disabled children in Ethiopia have the same rights as other children, and like other children, their rights are often not respected. However, unlike other children, those with disabilities are often excluded – from family life, their peers, their neighbourhoods, schools and the larger community – and are often ‘invisible’. This ACPF research project has tried to make the situation of disabled children more visible and their voices more audible, to ensure that parents, community leaders, policy makers, child rights activists and child rights organisations commit

to better protecting and promoting the rights of all children, including those with disabilities.

*“When we make our communities better places where children with disabilities can thrive, at the same time we improve life for everyone. Everyone benefits from better schools, access to health care, safer neighbourhoods and streets, and more community participation. When reaching out to parents, friends and neighbours we create the solidarity needed to build a better community and a society of social justice and human dignity”.*

Ransom 2009

### Key advocacy messages

- *Children with disabilities have a right to health, education and equality of work opportunity. Their voices should be heard by their parents, families, peers and communities, to combat exclusion and promote inclusion. The barriers to full participation for disabled children are too often caused by the low expectations of their parents and families, and the community’s lack of understanding of their interests and capabilities.*
- *Government, civil society organisations, communities and the private sector should work together to identify and learn from good practice in inclusive education, health care, work and employment opportunities, and in social and family awareness-raising. Both government and NGOs should develop inclusive policies based on good practice and implement these throughout the country.*
- *Programmes and budgets for improving the situation of disabled children must be specific, realistic and structured to ensure effective service delivery and the progressive implementation of disability-inclusive policies and practices. Both government and NGOs must monitor progress and evaluate services to identify problems and ensure accountability of action.*



## Appendices

### Appendix 1: List of quotes by Research Participants

Page number	Quote
iv	Disability does not mean inability. If our needs are met, we can be just as successful as our non-disabled peers. It is wrong to say that disabled children are unable to be independent. Deaf boy, 15
viii	Disability should not be seen as a disease. Disabled children can learn, play, work and perform just like other people without disability. All persons – those with disabilities and the rest of the community – should know this. Carer of a girl with an intellectual disability
1	Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.
6	Poverty is not simply the consequence of a lack of resources. Some people are unable to access existing resources because of who they are, what they believe or where they live. Such discrimination is a form of exclusion and a cause of poverty. Yeo 2001
29	People with disabilities are...starting to believe the concept of 'we can' for different issues. This helps them to cope with the challenges that they are facing. Teacher, key informant, Addis Ababa
29	She can't be independent so I don't think there is hope for her future. Institutional carer of an intellectually disabled girl
33	The community does not actively enquire to know about newly adopted government policies. Similarly, policy makers do not exert themselves to introduce new policies to the community. Community leader, key informant, Adama
33	I need supportive equipment. I can't go to school because I get tired walking, and need crutches or a wheelchair so that I can continue to learn. Physically disabled girl, 12
35	There are different factors impacting on my learning. My parents are both dead, so my sister is my primary carer. We have another sister who is also disabled, and our carer sister had to get divorced to support us both. We have no money for clothes, shelter or food. Visually disabled boy, 13
39	I want to learn and to help change my country. Intellectually disabled girl, 13
40	"This shows that children with disabilities have the capacity to do whatever it is that other normal people can do if we give them the opportunity to learn... However, in the absence of conducive environment for education after Grade 5, most of them are forced to abandon their education. So, we can say that the education given to children with disabilities is not sustainable and cannot secure their future economic and employment opportunity". (Key informant: teacher from Adama)

43	We tried to cure his injury with traditional medicine, but now we want to take him to a big hospital. Carer of a physically disabled boy
44	When we give birth, the children often get sick with something that can be cured easily, but when left untreated becomes a disability. We need better access to health institutions. Carer of a physically disabled boy
45	“You want to know about my problems? I have many. When I work I fall, and when I stand, I need help”. Physically disabled girl, 15
47	My father does not support any of the children in the household. My mother supports us all and does not have enough money to look after my additional needs. Physically disabled boy, 13
55	I don't know how my life will improve in the future, but if I get the opportunity, I want to be a doctor and improve my life. God will help me. Visually disabled girl, 9
58	In the end, we all wish to see a better future for children with disabilities. Carer of an intellectually disabled boy
59	Different institutions and individuals have not brought about the desired change to disabled children so you [researchers] better keep your promise and find a worthwhile solution. Carer of a boy with multiple disabilities
61	The bottom line of inclusive education, is how it meets the developmental and social needs of children with disabilities. Tirussew 2006 p 65
61	It would be good if teachers learnt sign language, especially if the rest of the community learnt too, so that we could all communicate together. Deaf girl, 16
61	All disabled children at every single house should be located and given the opportunity to learn. Carer of a deaf boy
64	As a disabled child I want to work as much as I can to help my community be free from the problems that I have faced. Plus, I want to raise awareness about children with disabilities. Physically disabled boy, 16
64	Financial support from foreign sources is not sustainable. It is better for the community to engage children with disabilities in income-generating activities, to show their partnership with the children. Carer of an intellectually disabled boy
67	When we make our communities better places where children with disabilities can thrive, at the same time we improve life for everyone. Everyone benefits from better schools, access to health care, safer neighbourhoods and streets, and more community participation. When reaching out to parents, friends and neighbours we create the solidarity needed to build a better community and a society of social justice and human dignity. Ransom 2009

## Appendix 2: A day in the life stories

*Note: names have been changed to protect privacy*

### 1. Rural disabled girl

Bethel wakes up at 6:30 each morning. She makes her bed and gets ready for church. She has a physical disability, caused by contracting polio as a young child, and finds it hard to use the toilet, which is very low to the ground. She doesn't complain about this to her carers, who are members of her extended family, as she doesn't think they can afford to build one that is accessible for her.

After church, she cleans the whole house. She cleans the floor with a cloth, which hurts her legs. Again, she does not tell her carers of this pain, because she feels bad. After cleaning, she makes breakfast for the family and gets ready for school. She is grateful to be able to go to school, despite having lost both of her parents, but she finds the walk very long and exhausting each day.

After school, she changes into her work dress and cleans the compound. This is tiresome as she must pick the fallen leaves from the trees by hand. She then washes the family's clothes by hand, putting the container on a chair to make it easier, and then fetches drinking water. Fetching water takes three trips because she cannot carry the bucket when it is full.

She takes a shower and then performs a coffee ceremony, which she enjoys being a part of, for the family before eating supper with them and washing up all the plates.

Bethel feeds the hens, which she is responsible for, then studies for school. After studying she rests: sometimes friends come and visit, or she might watch TV or sit on the porch in her favourite chair.

### 2. Urban disabled girl

Heren wakes up at 6 am. She makes her bed, before dressing herself and her sister. She goes to the toilet, which is frustrating because she must kneel to use it, before cooking breakfast for her family. Going to school is both exciting and tiring for her, as it takes her almost 30 minutes to walk there with her neighbour. She finds that, by the time she reaches the school compound, she is usually tired and late for class.

Today she arrived at school 30 minutes early, and had to sit and rest while her friends played in the playground until school began. The first lesson of the day is double maths, in which she is an active participant. Heren spends school playtime sitting and playing puzzle-like games with her friends. She really enjoys these games because she feels they are the only kind she can play without discomfort.

Once school is over for the day, she and her neighbour walk home. She does not rest when she gets home, but instead fetches water for the family with her friend. The water pipe is 10 minutes' walk from the house, and she has to make two trips to fetch enough water to last the family for the evening.

She plays with her brother and sisters for a while before returning to several chores, including cleaning the house and making the fire for her mother to cook their dinner.

After dinner, she studies for an hour before going to bed at 8 pm.

### ***3. Urban non-disabled girl***

Rigbe gets up at 5 am to practice long-distance running with her friends for an hour. After her run, she cleans the barn for the animals and takes a shower. She then prepares coffee and breakfast for her family.

After breakfast, she walks to a disabled friend's house and together they continue to school. It takes her 30 minutes to walk to school because her friend finds it difficult to walk fast and, once they have arrive, she plays games like hide-and-seek or skipping with friends until class begins.

She doesn't pay much attention in her morning classes, but at playtime she plays for a while and then goes to the library to finish her homework, which is due in the afternoon.

After class, she meets her neighbour and returns home with her. She helps her friend fetch water for her family, before returning home and cooking dinner for her own family. After cooking, she spends half an hour milking the cows before eating quickly and going to another neighbour's house to watch TV.

At 10 pm she comes back from her neighbour's house and goes to bed.

### ***4. Urban disabled boy***

I wake up at 6 am on weekdays. I get dressed and wash my face to eat my breakfast, with help from my mother and sister. I find it difficult to use the toilet, because I can't sit comfortably due to the problems with my leg muscles. Some days I do sports exercises in the mornings, which makes me happy. Today, I was frustrated because my sister failed to make breakfast on time, and I was late for school on a day I have exams.

I go to school with friends from my neighbourhood, and I am the highest achieving student in the school. I have received numerous awards. I have never felt discrimination from my friends, and I get good care and support from my teachers. The sports teacher does not let me take part in sports lessons, which makes me sad. I am also sad when people see disability as a curse from God.

All people should be evaluated on the basis of their merit, rather than physical appearance.

After school, I eat lunch and rest for a few minutes, before helping my mother make *akenbalo*, the family's main source of income. I am proud to help my family, and I feel that I deserve to eat because I work.

After helping my mother, I watch a movie with my friends, before studying. I like to read, especially psychological and philosophical books, but I cannot afford these books often.

I go to sleep at about 9 pm, in the bed I share with my mother.

### **5. Rural non-disabled boy**

I get up at 7 am on weekends. After washing my face and having breakfast, I go to work in my family's farm until lunchtime, because it is the weekend so I am not in school. I am happy when I see the farm's products that I have helped to work on.

I eat lunch at 1 pm, and then play and talk with my family until 2.30 pm. I love my family, and they love me. In the afternoon, I herd the cattle in the field while playing with my friends, which I enjoy very much.

From 7 pm until 8 pm I study with my father, who is a teacher. Then my mother helps prepare my bed and I wash, before praying – which makes me happy because I believe in God.

### **6. Rural disabled boy**

I get up at 7 am, get dressed, wash my face and use the toilet without any help from my family. My mother prepares my breakfast while I fetch water from the river, before going to school. I live with my mother and sister, who I love and want to help support.

I go to school with friends from my neighbourhood, who support and encourage me. I study and come home for lunch. I spend the afternoon in the fields herding my family's cattle, which I enjoy because my friends are there too, and we play football and other games. I get upset, and sometimes cry, because I am only allowed to play goalkeeper, due to the problem with my legs. My friends tell me I am the best goalkeeper and this makes me feel better, because they care and support me. On the way home, I collect firewood for my mother.

I study at night from 7 pm until 9 pm. My mother prepares my supper and my bed. I wash my leg and pray to God to heal it with my mother, before going to bed on the ground.



## References

- Asefa A. (2008). *Status of victim assistance in Ethiopia report*. [Presented to the standing committee on victim assistance and socio-economic reintegration in Geneva, 3 June 2008]. MoLSA.
- Asrat A. (2010). *Special needs education: a challenge that needs to be addressed*. Walta Information Centre. Available at [www.waltainfo.com/index.php?option=com\\_content&task=view&id=6570&Itemid=82](http://www.waltainfo.com/index.php?option=com_content&task=view&id=6570&Itemid=82) [accessed 03.06.10].
- Chernet. (2007). [Chernet Tekle Weldeab & Liv Randi Opdal (2007) Raising a child with intellectual disabilities in Ethiopia: What do parents say?, Paper Accepted for Presentation at Refereed Conference of the American Educational Research Association, Chicago, Illinois].
- Central Statistics Authority. (2008). *Summary and statistical Report of the 2007 population and housing census*. FDRE population census commission. Addis Ababa.
- CSA: See Central Statistics Authority.
- Education for All Fast Track Initiative. (2010). *2009 Annual Report*. Available at: [www.educationfasttrack.org](http://www.educationfasttrack.org) [accessed 05.05.10]
- Guarcello L. and Rosati F. (2007). *Child labour and youth employment: Ethiopia country study* [SP discussion paper no. 0704]. World Bank.
- Hailu E. (2010). *Sign language news at Addis Ababa University*. Available at: [www.signwriting.org/archive/docs6/sw0557-SignLanguage-AddisAbabaUniv.pdf](http://www.signwriting.org/archive/docs6/sw0557-SignLanguage-AddisAbabaUniv.pdf) [accessed 27.05.10].
- Lewis I. (2009). *Reaching the marginalized: education for disabled people in Ethiopia and Rwanda* [background paper prepared for the Education for All Global Monitoring Report 2010].
- Ministry of education. (2005). *Ethiopia education sector development program III (ESDP-III) 2005/2006-2010/2011 (1998-2002 EFY): program action plan*. FDRE. Available at: [http://planipolis.iiep.unesco.org/upload/Ethiopia/Ethiopia\\_Education\\_Plan\\_August\\_2005.pdf](http://planipolis.iiep.unesco.org/upload/Ethiopia/Ethiopia_Education_Plan_August_2005.pdf) [accessed 31.10.10].
- Ministry of labour and social affairs. (1996). *Developmental social welfare policy*. FDRE.
- Ministry of labour and social affairs. (2004) *Ethiopia's national plan of action for children (2003-2010 and beyond)*. FDRE.
- Ministry of labour and social affairs. (2005). *Country response to the questionnaire on violence against children*. FDRE.

MoLSA: See Ministry of labour and social affairs.

Mont D. (2007). *Measuring disability prevalence* [social policy discussion paper no 0706]. World Bank.

Ransom B. (2009). *Missing voices: children with disabilities in Africa*. ACPF.

Tirussew T. (2006). 'Overview of the development of inclusive education in the last fifteen years in Ethiopia'. In Savolainen H., Matero M. and Kokkala H. (eds). (2006). *When all means all: experiences in three African countries with EFA and children with disabilities*.

UNDP: See United Nations Development Programme.

United Nations Development Programme. (2009). *Human development report 2009: overcoming barriers: human mobility and development*. Available at: <http://hdr.undp.org/en/reports/global/hdr2009> [accessed 12.06.10].

Yeo R. (2001). *Chronic poverty and disability*. Action on Disability and Development.

Zelege S. (PhD), 2010, *Gender, disability and development: discussion paper* [paper presented at a panel discussion on gender, disability and development]. Poverty Action Network of Ethiopia (PANE): Addis Ababa. Available at: [www.pane.org.et/Portals/0/Gender,\\_Disability\\_and\\_Development\\_Discussion\\_Paper\\_Final\\_Report.pdf](http://www.pane.org.et/Portals/0/Gender,_Disability_and_Development_Discussion_Paper_Final_Report.pdf) [accessed 31.10.10].









**The African Child Policy Forum (ACPF)**

P. O. Box 1179, Addis Ababa, Ethiopia  
Telephone: +251 11 662 8192/96/97/99  
Fax: +251 11 662 8200  
E-mail: [info@africanchildforum.org](mailto:info@africanchildforum.org)  
Website: [www.africanchildforum.org](http://www.africanchildforum.org)

© 2011 ACPF