COMMUNITY MAPPING STUDY: PEOPLE WITH IMPAIRMENTS IN MUSANZE DISTRICT

Education, Equity and Empowerment (EEE) Project

Jubilee Action in partnership with Fair Children/Youth Foundation (FCYF)

December 2013

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The completion of this report would not have been possible without the active participation of a large number of individuals and organizations who deserve special thanks.

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We genuinely appreciate the specific support of the National Federation of Persons with Disabilities to their active participation throughout the community mapping process.

Finally, we would like to express thanks to everyone who shall use the community mapping findings to improve and protect children with disabilities rights in the near future.

Elie Nduwayesu

Executive Director

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LIST OF ACRONYMS

CSPro	Census and Survey Processing System
EEE	Education, Equity and Empowerment
FCYF	Fair Children and Youth Foundation
HI	Hearing Impairment
II	Intellectual Impairment
JA	Jubilee Action
MINALOC	Ministry of Local Government
NCPD	National Council of People with Disabilities
OI	Other Impairment
PI	Physical Impairment
PWI	People (Persons) With Impairment
PWD	People with Disabilities
SI	Speech Impairment
SPSS	Statistical Package for the Social Sciences
UNICEF	United Nations Children's Emergency Fund
VI	Vision Impairment

EXECUTIVE SUMMARY

In January 2013, Jubilee Action in partnership with Fair Children / Youth Foundation launched Education, Equity and Empowerment (EEE) project which aims to advocate for the rights of people with impairments and specifically to support those with hearing and communication impairments to gain access to education. This project acknowledged the gaps in reliable data about people with impairments in the Musanze district and so began the process of mapping people with impairment in April 2013.

The three stage methodology designed by the team ensured that detailed information was also captured about the EEE project target group: children and youth with hearing and / or communication impairments.

The outcome of the mapping study found 8,117 people living with impairments. 63% were over the age of 25 years. Of the remaining 37% aged 3-25, 841 people were found to have a hearing or communication impairment (many of which were found to have multiple impairments). Due to the project team's restricted time and resources to gather detailed data about the entire 8,117 people living with impairments, instead the team focussed on collecting detailed data about their target group plus a sample of the remaining people with impairments.

The detailed data showed 45.9% of people living with impairment had no access to education despite 74% of respondent confirming there was a nearby school. This indicates barriers to access which are not geographical and supports the government's efforts to ensure education access for all but emphasizes the exclusion that minority groups with disabilities continue to feel.

On average 20% of families indicated that stigma has a real impact of the lives of people with disabilities. We would suggest that this number is in fact even higher due to the limitation of gathering data from children who may be unable to communicate in a traditional way.

Our report serves as evidence of the need for further interventions to support children and youth with disabilities to ensure their access to education and their active participation within their communities.

1. INTRODUCTION

A recent national census on people living with disabilities found that despite improvements in national legislation, people and especially children who live with disabilities face great discrimination and stigma in Rwanda (UNICEF Rwanda: 2011).

One of the recent priorities for the leadership of Rwanda has been to improve protection of children from violence, abuse, exploitation and discrimination. Children with disabilities are particularly prone to discrimination from the very individuals and institutions with an obligation to protect them, including families, health and education services. This discrimination often leads to reduced access to basic social services, especially education, as a result of the lack of recognition of their equal humanity and capacity by their families, peers and communities.

They are also especially vulnerable to abuse, exploitation and neglect, due to the same misperceptions, and this is further exacerbated due to their increased vulnerability as a direct result of their specific physical or intellectual difference.

In February 2008, FCYF established a School for the Deaf in Nyange Sector. The objectives of the school were to increase awareness for the rights of children with hearing impairments and to prepare children for mainstream school (inclusive education). The school has seen great success since its opening and has successfully integrated 17 deaf children into mainstream school, but FCYF has also recognised the barriers and challenges faced when reintegrating deaf children into the community. These challenges inspired the design of the EEE project which aims not only to continue to provide education services to children with hearing impairments and community difficulties, but also to build the capacity of the state by offering robust data about children and youth with impairments, training school teachers in inclusive education, as well as breaking down stigma within the community through advocacy initiatives.

The main purpose of the community mapping study undertaken by FCYF in Musanze district was to identify the target group of their recently established EEE project (children and youth with hearing and / or communication impairments). However, upon notifying district representatives of the National Counsel for People with Disabilities (NCPD) they were requested to also data as much information about other people with other impairments in the district. This broader data set was also useful in order to successfully advocate for the rights of all people living with impairments.

It was intended that the collected data would not only be used to advocate for vulnerable children but would also inform decision makers at all levels.

It is for the above reasons that the community mapping study has been conducted with direct collaboration and support from the district of Musanze and from the local entities.

2. COMMUNITY MAPPING STUDY

2.1 Objectives

The community mapping study had three specific objectives:

i. To identify all people living with impairments in the district;

ii. To gather detailed information about those children and youth aged three to 25 years with a hearing and/ or communication impairment (EEE target group) in Musanze district;

iii. To conduct a study on stigma amongst people with disability in the district (experienced, anticipated and self-stigma).

2.2 Scope of work

This community mapping study was conducted in the whole district of Musanze as part of the first of three community mapping studies which will be associated with the FCYF and Jubilee Action EEE project. This same mapping exercise will be duplicated in 2 other districts namely Gakenke and Burera before 2015.

2.3 Data collection methodology

2.3.1 Data collection tools

A Questionnaire was the data collection tool of choice used during the community mapping study. In order to meet the objectives of the study, three forms were designed: the first to capture basic profile of all people with impairments in the district. The second form to the shape of a questionnaire which captured more detailed information about those people who fell into the EEE project target group, together with detailed information for a 30% sample of all other people who had been identified at stage one as having a disability. Whilst the third form, also a Questionnaire, was intended to collect information on 'experienced', 'anticipated' and 'self' stigma identification amongst a sample of those who completed the second, detailed questionnaire.

2.3.2 Community mapping timeframe

From the planning phase, up to the last phase of dissemination of the community mapping findings, the whole process took a period of 7 months.

- April: Planning phase and design of data collection tools;
- May-August: Implementation phase (logistical arrangements, training of the EEE team assigned the data collection tasks, data collection from the field);
- September-October: Data processing (design of data entry matrix in CSPro, training of data entry clerks, data entry, data cleaning and tabulation), analysis as well as the dissemination of the community mapping findings.

2.3.3 Community mapping process

As far as the design and implementation of the community mapping study is concerned, there were three phases under which the data collection was undertaken. The summary of these three implemented stages are captured here below:

Stage 1: Village level scoping

First and foremost, a meeting which targeted the six selected persons in each and every village was organized at cell level. The meeting aimed at providing briefings to the community representatives about the objectives of the community mapping study and defined the stakeholders' roles and responsibilities so that they could help to identify the people with disabilities at village level.

The six community representatives who assisted the whole data collection process are:

i. *Head of Village*: He/she is a community leader and is in the best position to provide information on people with disability in his/her area of operation.

ii. *Health community worker at village level*: As the Health community worker deals with the health issues, he/she provided useful information for disability mapping in the village.

iii. *Women representative at village level:* Gender issues in general and child protection issues in particular were regarded as the critical areas to take into account during the community mapping study. The Women representative at the village level played a vital role in ensuring that all the child protection cases were reported and all the disabled persons especially females were identified.

iv. *In charge of information at the village level:* Since the person in charge of information at the village level is updated on each and every thing happening in his/her village, his/her contribution on identification of disabled people was very critical.

v. *Representative in charge of social affairs as elected by the community:* The social affairs person conducts regular visits to each and every household in his/her area of operation. Therefore, he/she was in the best position to provide useful information on disabled people at the village level.

vi. *Representative of any religious organization, of any denomination:* The fact that most of Rwandans belong to religious organizations, the representatives of religious organizations are influential people and are updated on conditions of living of their religious organizations members. They participated actively in the identification of the disabled people in their respective villages.

Some weeks after the initial briefing, these six representatives were asked to meet the project team in order to document a record of all persons with impairments in their respective village. At this stage, the representatives were briefed with some standard disabilities categories, but were largely allowed to document the impairments with their own descriptions. The data collection tool used at this stage can be found at annex one.

Stage 2: Targeted community based interviews

During the second stage of the process, all people with disabilities were called to Cell level in order to verify the data provided by each of the six village representatives at stage 1. Once this process was completed, the EEE project target group (children and youth with communication disorders and hearing impairments) and a sample of 30% of children and youth with other disabilities, who are between 3-25 years old, were met and invited to attend a meeting with a field worker. During the meeting, the detailed assessment was undertaken, during which time the field worker completed the stage 2 Questionnaire (see annex two).

The individual interviews took place at a selected building within the community which could be easily accessed by everyone.

Stage 3: Targeted follow ups

This stage targeted the same group of people as stage 2 but aimed to reach those who did not participate in the community-based second stage due to stigma or any other reasons. This stage involved community outreach by the team to reach individual homes so that the root causes of stigma and other associated challenges they might be facing could be identified. In some cases, at stage two, parents reported their children as living with a disability; during stage 3, these children were visited, to ensure that they actually did have the disability that their parents claimed.

The team involved in data collection were briefed by a qualified Speech and Language Therapist and Audiologist, the latter provided by VSO, about the assessments that could be undertaken to determine the type of impairment that was presented and also to ensure that the impairment had not been misunderstood by the community. During this stage, health and education facilities were also recorded and mapped.

2.4 Stigma identification:

The mapping team also developed a questionnaire which captured the information about 'experienced', 'anticipated' and 'self' stigma. Over 600 people were interviewed using this questionnaire at the second and third stage through a process of random sampling. The purpose of gathering this information was to ensure that the impact of the EEE project advocacy in the local community can be evaluated throughout the project lifetime. Where possible children and parents were interviewed separately. This was in case parents were the source of the stigma. In cases where children experienced difficulties of communication, neighbours were also interviewed as they were considered to provide less biased information.

2.5 Child Protection:

During the mapping study, a format was designed to capture child protection special cases in such a way that they are documented and referred to the social welfare services as appropriate. All forms have been submitted to the District and a follow up process will be implemented throughout years two and three of the project. There were many extreme child protection issues that arose due to the lack of appropriate health and social care towards children and youth with severe impairments, but also many more health related issues which were arising due to poor hygiene and lack of education about

preventing infection, and maintaining a healthy lifestyle. Although these issues fall outside of the remit of the EEE project, referrals were made through the child protection form where possible and basic advice was given by the project team where appropriate.

2.6 Data Processing:

Data collected from the field was processed using CSPro software for data entry and SPSS software for data cleaning and analysis.

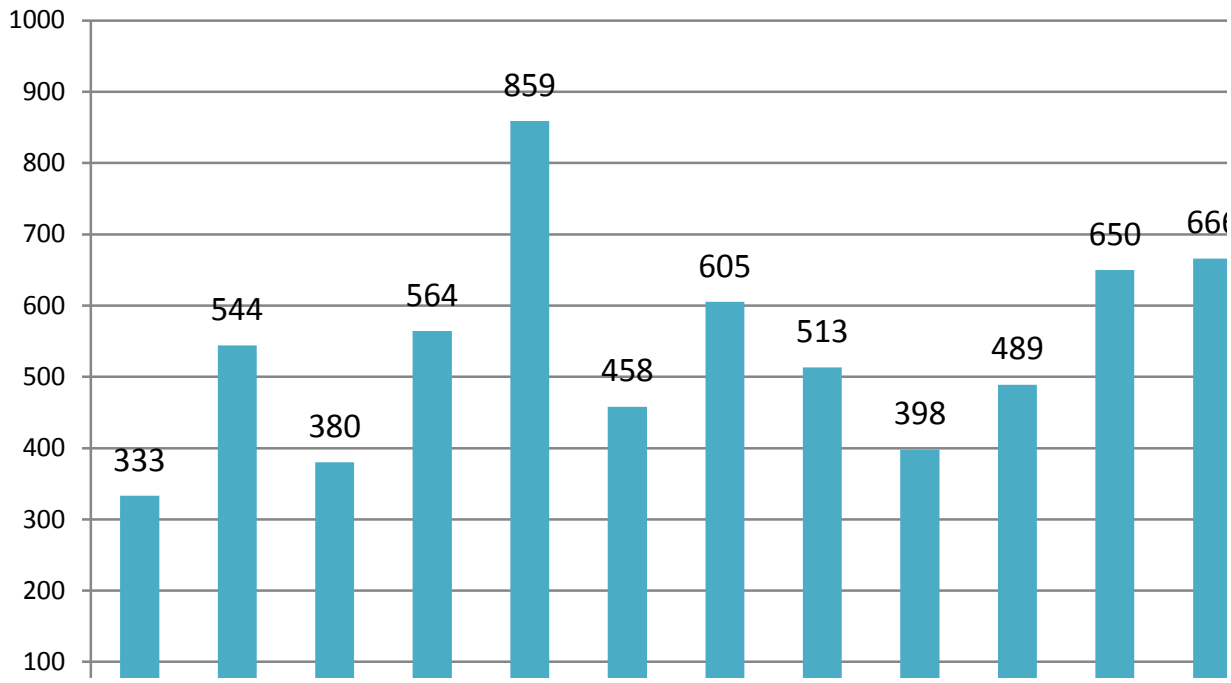
3. Presentation of Findings

3.1 All people with impairments in Musanze district

This section presents the data collected during the community mapping study about all people living with impairments in Musanze district.

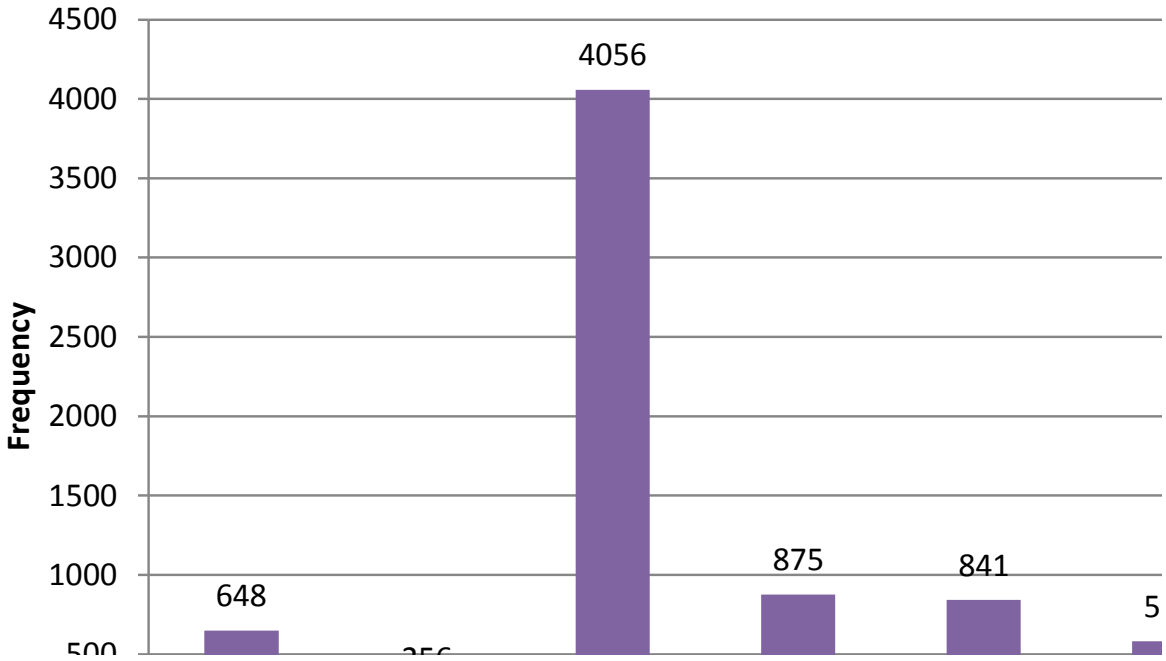
8,117 people were found to be living with one or more impairments in Musanze district. The chart below shows the geographical location of people with impairments. Musanze and Nyange sectors presented the highest number of people with impairments. The lowest number of people with impairments was found in Busogo and Muhoza.

FIGURE 1: NO. OF PEOPLE WITH IMPAIRMENTS, BY SECTOR IN MUSANZE DISTRICT.



Many different types of impairments were identified. Physical impairments far outweighed the other categories of impairments.

FIGURE 2: NO OF PEOPLE WITH IMPAIRMENTS BY TYPE OF IMPAIRMENT



Of the 8,117 people with impairments identified, 5,181 were identified as over 25 years old. The table below presents the number of people with impairments by sector, gender and age group:

FIGURE 3: TOTAL NUMBER OF PWI BY SECTOR GENDER AND AGE GROUP.

SECTORS	25 YEARS OF OR UNDER			ABOVE 25 YEARS			ALL PWIs		
	M	F	Total	M	F	Total	M	F	Total
BUSOGO	60	40	100	115	118	233	175	158	**333**
CYUVE	141	121	262	197	191	388	338	312	**650**
GACACA	102	94	196	154	133	287	256	227	**483**
GASHAKI	79	67	146	115	137	252	194	204	**398**
GATARAGA	102	77	179	172	193	365	274	270	**544**
KIMONYI	62	42	104	136	140	276	198	182	**380**
KINIGI	149	117	266	164	134	298	313	251	**564**
MUHOZA	67	78	145	130	95	225	197	173	**370**
MUKO	104	86	190	134	165	299	238	251	**489**
MUSANZE	135	121	256	254	349	603	389	470	**859**
NKOTSI	110	73	183	119	156	275	229	229	**458**
NYANGE	210	145	355	211	239	450	421	384	**805**
REMERA	91	87	178	211	216	427	302	303	**605**
RWAZA	111	67	178	162	173	335	273	240	**513**
SHINGIRO	111	87	198	217	251	468	328	338	**666**
TOTAL	**1634**	**1302**	**2936**	**2491**	**2690**	**5181**	**4125**	**3992**	**8117**

The data were obtained from the active participation of both community members and EEE project throughout the three data collection stages and were being updated at each and every stage. The total number of people with disabilities in Musanze district was 8,117 which represent 2.6% of the total population while it was 4.8% according to the previous census conducted in November 2010 by the African Decade of persons with Disabilities (ADPD) in collaboration with the Ministry of Local Government. We assume that this difference is due to the data collection process previously used by other organisations whereby the results from sample populations were multiplied, resulting is a larger number. We intend to investigate this further.

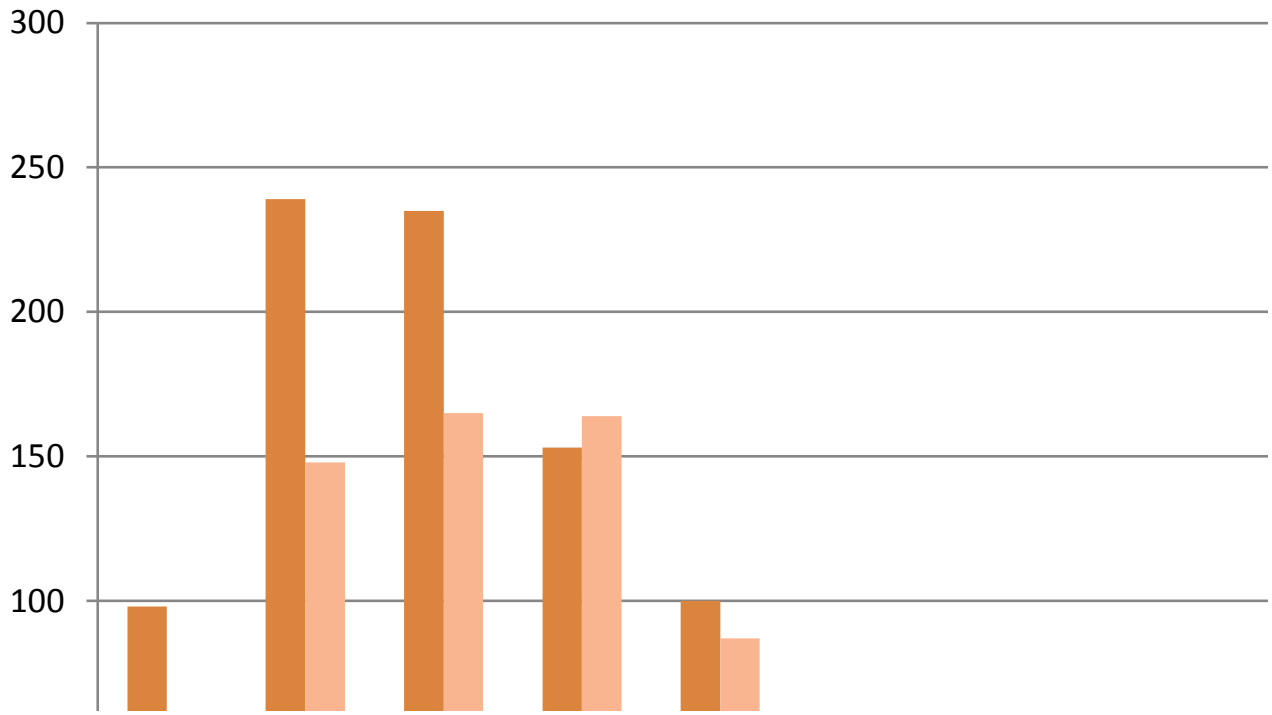
3.2 Detailed assessment results (Stage 2 and 3)

The following data is relevant only to 1,528 respondents: 810 of which were found to have hearing and/or communication impairments, including multiple impairments and therefore fell into the EEE project target group. The remaining 718 represent a sample of all other people with disabilities aged 3 to 25. Hereafter the 1528 respondents will be referred to as the "sample population". Despite our stage

1 findings indicating 841 in the EEE project target group, it is important to acknowledge that 31 beneficiaries were not met at stage two or three which can be attributed to the variety of reasons including access, stigma, communication and other unknown barriers.

Nearly 95% of the respondents in the graph below were children and youth (aged 3-25) as this was the age group targeted by the EEE project, however, there were a few exceptions to this age group and this occurred due to 1) age groups estimates at stage 1 were not accurate and 2) some people with impairments showed up to complete a questionnaire and were not turned away. The figure below shows both the gender and age group of all respondents; 56.7% and 43.3% for male and female respectively.

FIGURE 4: RESPONDENTS BY AGE GROUP AND GENDER



The large proportion of the respondents was below 15 years and these largely account for the children youth who are not married. The statistics from the table below shows that 36.2% of the respondents were single, 1.8% were married while only 0.3% were reported to be widows.

FIGURE 5: RESPONDENTS' MARITAL STATUS

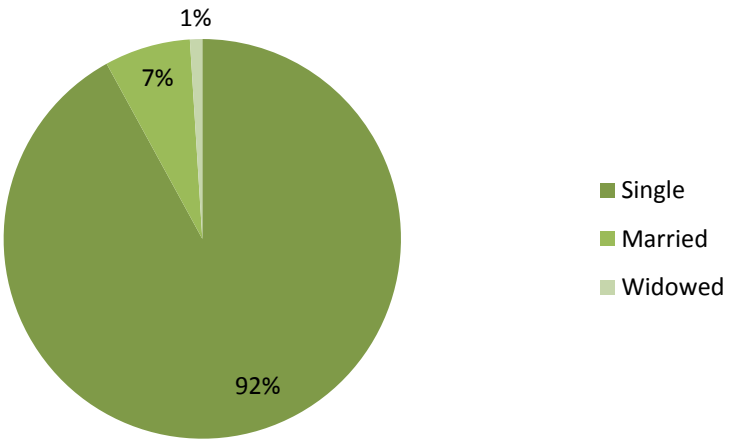
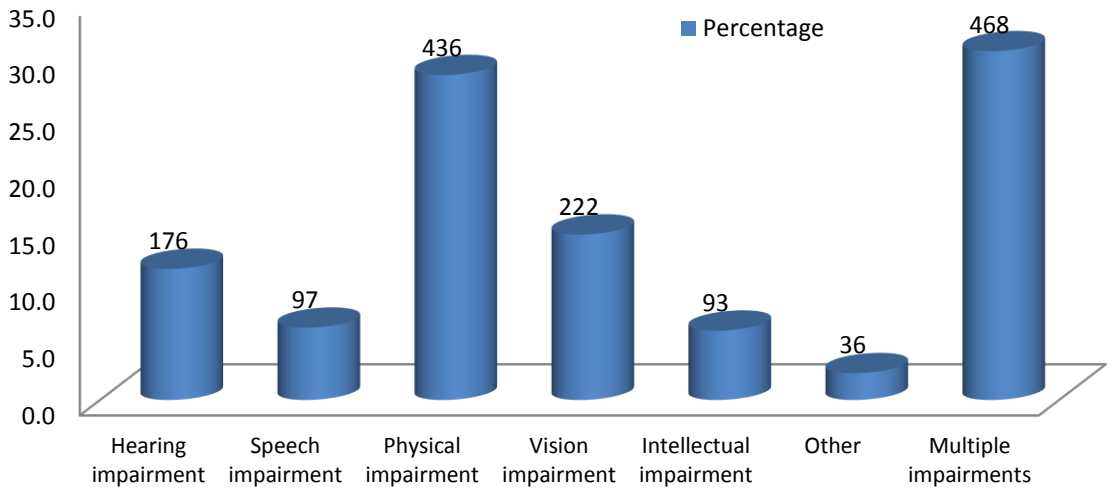


FIGURE 6: RESPONDENTS BY IMPAIRMENT



The following figure above gives the clear picture about impairments of our respondents. 436 people were identified with physical impairments; the largest single impairment category. The impairments which were commonly identified in the 'other' category are shown below. It was noted that 72 children/youth state that they have disabilities other than physical, vision, speech, hearing and intellectual as summarized earlier on the type of impairment. When they were asked to specify the type of their disability, more than half (56.9%) said that they are epileptic while 13.9% of them were albinos and children/youth with hump at the back were 13.9%. Those who mentioned other type of disability

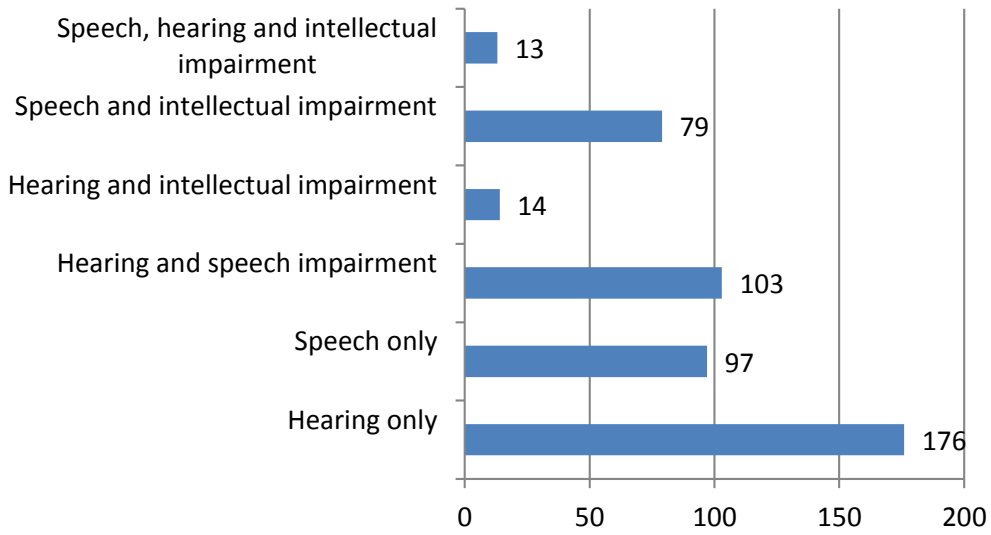
were 15.3%. These could be for example people with skin problems, without sex organs, people who got burnt, etc.

FIGURE 7: 'OTHER' TYPE OF IMPAIRMENT

Type of Impairment	Frequency	Percentage
Albinos	10	13.9
Epilepsy	41	56.9
Hump	10	13.9
Others	11	15.3
Total	72	100

Multiple impairments were also identified very frequently. Critical for the EEE project was the identification of children and youth with any combination of hearing and speech impairment together with other impairments. This information will be used to identify those children who will undergo a further screening to assess their capacity to attend mainstream school if provided with support. Figure 8 gives an indication of the number of people with hearing, communication and multiple impairments.

FIGURE 8: HEARING, COMMUNICATION AND MULTIPLE IMPAIRMENTS OF RESPONDENTS



During the community mapping study, discovering the root causes of impairment was critical for planning and decision making purposes. It is possible that some causes of impairments may be prevented while others were congenital.

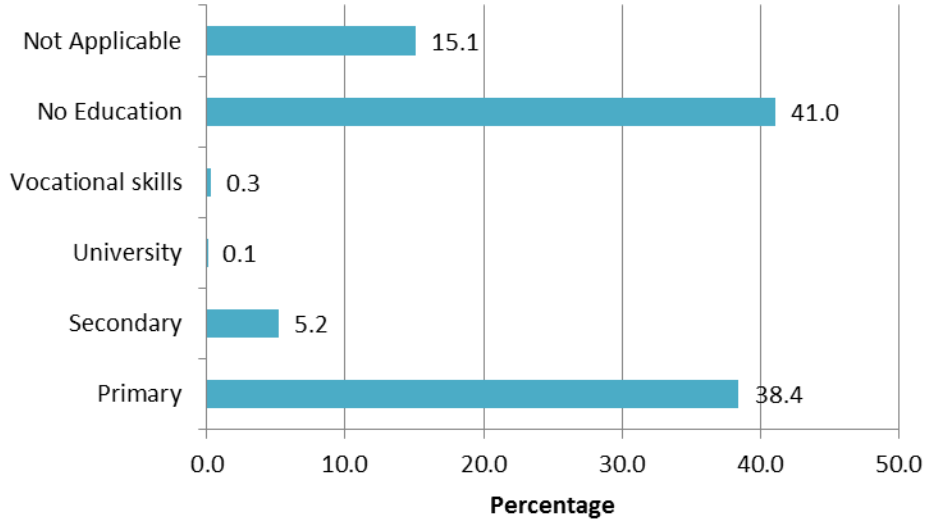
Figure 9 shows us that 54.1% of the disabled children/youth were born with disability while 34.1% of disabilities resulted from sickness. Respondents whose disabilities were caused by an accident represented 7.6% while those who became disabled due to the war was nearly 1%. For the disabilities

caused by sickness, a comprehensive research study aimed at identifying the types of diseases as well as their root causes should be commissioned so that intervention strategies are developed accordingly and up to 34% of these disabilities can be prevented.

FIGURE 9: CAUSES OF IMPAIRMENT

Attributed cause	Frequency	Percentage
Born with	827	54.1
Sickness	521	34.1
Accident	116	7.6
War	13	0.9
other	31	2
Not specified	20	1.3
Total	1528	100

FIGURE 10: LEVEL OF EDUCATION



The level of education of respondents is summarized in the graph above. Those who were below age 6 (primary entry level) were marked as not applicable.

It was noted however that children and youth with no education represented 41% which is very significant. The reasons associated to this could be for instance the mindset for both children/youth with disability and their parents, level of disability (physical impaired), mentally affected or a school may be located at far distance, etc.

There were many disabled youth (over 16 years) who were considered to be able to attend a vocational school and thus acquire enough knowledge which could help him/her to be self-reliant. To this end, we

urge the district and other development partners to use our data and undertake a more detailed screening process to identify vocational education opportunities for youth with impairments.

In order to understand the reasons why such a high number of respondents had no education at all, we asked respondents to tell us whether there is a nearby school. The definition of nearby was left to the respondent to interpret. The results of this question are summarized here below.

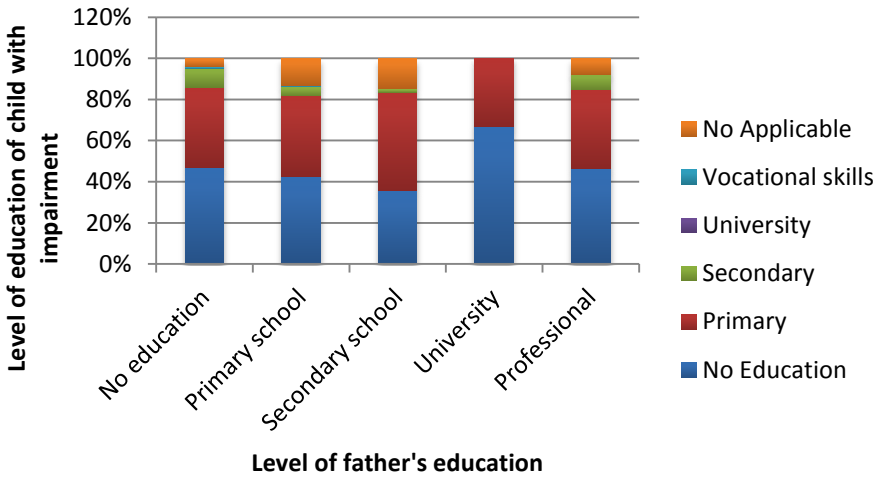
TABLE 11: RESPONDENTS WHO IDENTIFIED A SCHOOL NEARBY

	Frequency	Percent
Yes	1128	73.8
No	24	1.6
Not specified	376	24.6
Total	**1528**	**100**

Though most of the respondents stated that there is a nearby school to their homes, they expressed that these schools are meant for children without disability and/or children with little disability who can manage to walk by themselves. There are some disabled children who use wheel chairs and who cannot manage to go to school. We therefore would like to advocate for schools to adapt their physical infrastructure to ensure accessibility for physically impaired children and for existing schools to offer peer educators to support these children in accessing school.

There is thought to be a correlation between parents' education and education of their children due to factors such as the value of education and the family's ability to afford costs associated with education. However, no such correlation was found during our mapping process. This only emphasises the barrier of stigma faced by children with impairments. Figure 12 shows that a father's level of education does not affect the education of their children with impairments.

FIGURE 12: FATHERS EDUCATION



When we also consider the education level of the mother, we have been able to identify a positive correlation between the education of parents and the education of their children with impairments. 51% of children with impairments whose mother *and* father have not obtained even a primary education were identified as having no education. However, when both the child's mother *and* father have *at least* a primary education, only 41% of children with impairments have been identified as having no education.

Mother's education is paramount for the education of her children in general and for disabled children in particular. Educated mothers are in better position to handle issues of gender equality and child protection which have been a top priority of Rwanda leadership.

FIGURE 13: FATHERS OCCUPATION

Occupation	Frequency	Percentage
Not applicable	407	26.6
Farmer	952	62.4
Others	28	1.8
Constructer	29	1.9
Carpenter	8	0.5
Shop dealers (Gross and small Retailers)	16	1
Teacher	7	0.5
Work in Security companies	19	1.2
Employee	11	0.7
Driver	7	0.5
No job	44	2.9
Total	1528	100

The fact that most of Rwandese live in rural areas leads to the fact that the majority of disabled children's fathers are farmers (cultivators) and some of them cannot afford to cater for some specific needs for children who are disabled.

FIGURE 14: MOTHERS OCCUPATION

Occupation	Frequency	Percentage
Farmer	1192	93.6
Shop dealers (Gross and small Retailers)	14	1.1
Teacher	5	0.4
Tailor	2	0.2
Others	5	0.4
No job	55	4.3
Total	1273	100

The information provided by our respondents confirmed that the majority of both fathers and mothers are farmers.

FIGURE 15: SIZE OF THE FAMILY

Family size	Frequency	Percentage
1-2 Persons	161	10.5
3-5 persons	**632**	**41.4**
6-9 persons	580	38
10-13 persons	67	4.4
Not specified	88	5.8
Total	1528	100

FIGURE 16: LAND POSSESSION

Land possession	Frequency	Percentage
Households with land	1208	79.1
Households with no land	320	20.9
Total	1528	100

The outcome of the survey to determine land possession is not surprising given that a large proportion of respondents are farmers; it follows that most of them own land for cultivation. This is significant because there is a reliance on labour to produce food for the family. This may account for the reason why some children do not proceed to secondary school, but instead provide much needed labour to cultivate the land owned by their family.

FIGURE 17: HOUSE OWNERSHIP

House ownership	Frequency	Percentage
Households with House	1347	88.2
Households with no House	181	11.8
Total	1528	100

The results show that the majority of respondents (88.2%) stated that they own a house though this data can be misleading. The standard of 'houses' varies dramatically and so we have provided pictures of a typical house which is referred to in the above data; poorly constructed and inadequate to provide basic care and infrastructure for children with impairments

Note: Here below is the sample of the houses visited during the community mapping.

FIGURE 18: DOMESTIC ANIMAL POSSESSION

Domestic animal possession	Frequency	Percentage
Households with a domestic animal	644	42.1
Households with no domestic animal	884	57.9
Total	1528	100

As most of the parents of children with disabilities are farmers, we wanted to find out if they own a domestic animal as this could be very helpful for them in terms of income generation. The findings show that only 42.1% own a domestic animal while 57.9% stated that they do not have a domestic animal.

FIGURE 19: SPECIFICATION OF THE DOMESTIC ANIMAL

Type of animal	Frequency	Percentage
Cow	224	34.8
Goat	98	15.2
Sheep	143	22.2
Pigs	49	7.6
Sheep and Goats	10	1.6
Hens	16	2.5
Cow and Sheep	22	3.4
Cow and Goats	21	3.3
Not specified	61	9.5
Total	644	100

Wanting to know the type of domestic animal that they own, 36.1% specified that they have at least a cow while 23.1% own sheep and 15.8% of them have goat.

TABLE 20: FAMILY CATEGORY

Family category	Frequency	Percentage
Not specified	26	1.7
Abject poverty	90	5.9
Very Poor	501	32.8
Poor	888	58.1
Resourceful Poor	23	1.5
Total	1528	100

From the answers provided in the above three figures, it is clear that most of rural communities belong to the 2nd and the 3rd family category which are the categories of “Very Poor” and “Poor”. The resourceful poor were only 1.5% while the abject poor represented almost 6% of the total population interviewed. A description of family categories can be found at Annex 4.

3.2 Stigma Identification

A recent national census on people living with disabilities found that despite improvements in national legislation, people and especially children who live with disabilities face great discrimination and stigma in Rwanda.

In order to understand the 'experienced', 'anticipated' and 'self' stigma felt by children and youth with impairments, a random sample of 663 respondents were asked to complete a stigma questionnaire alongside their stage 2 mapping interview. The definitions of stigma used in our mapping are described below:

Experienced Stigma	Anticipated Stigma	Self Stigma
Actions or feelings influenced by negative attitudes of behaviours which have occurred	Actions or feelings influenced by the **anticipation or fear** of stigmatisation (which has not yet have occurred)	Negative beliefs or thoughts about themselves

The outcomes of the stigma survey follows.

Experienced Stigma

When asked "Does your child have as equal an opportunity to go to school as other children?" 65.2% of the parents of the children with disability said that their children have an equal opportunity to go to school as other children while 23.4% disagreed. There were other parents who stated that sometimes their disabled children have or do not have an equal opportunity to go to school as other children. This could be attributed to the parents' mindset or to other reasons as the parents cannot cater for their disabled children's basic needs (e.g. wheel chairs for those who have physical impairment for instance).

After that some parents had confirmed that their children do not have or sometimes have equal opportunity to go to school like other children, we wanted to find out how big a problem this is considered as this is an opportunity to understand how much the parents value education for their children. 49.6% of respondents said that the problem is large and 35.7% stated that the size of the problem is medium while 12.1% confirmed that the problem is small. Those who said that there is no problem were only 2.7%.

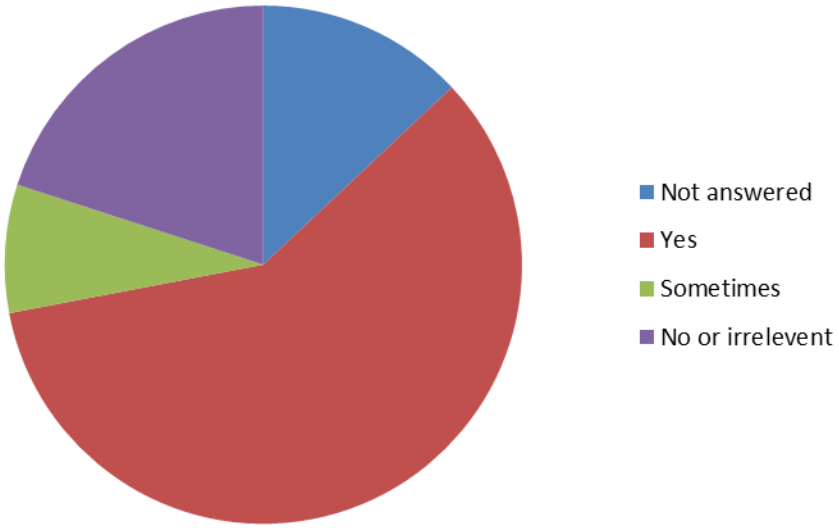
When asked "Does your child take part in major family /community festivals and rituals as other children do?" nearly 59.4% said Yes while 22% disagreed and 16% acknowledged only 'sometimes'. Of those who said "no" or "sometimes", only 8.4% of respondents acknowledged that this was not a problem while 28.7% admitted it to be a small problem, 30.7% admitted a medium problem and 32.3% admitted it to be a large problem.

19.3% of parents reported to us that that their children did not visit other people in the community as other children do.

When asked if the children with a disability take part in sports or other recreational activities as often as other children do, 53% agreed while 31% disagreed. Those who neither agreed and nor disagreed stated that sometimes they do. Only 11% of parents who disagreed consider this to be no problem at all indicating the acknowledgement of parents that their children do wish to be included. Even though physical impairment was assessed to be the highest in the district, children with other disabilities should be participating as actively in sports or other recreational activities as often as other children do. This is due mostly to the mindset of other children and parents which can be changed progressively if the community are taught that how they should treat disabled children like others and are informed that games and sports can be adapted to be inclusive for all abilities.

When asked "in family discussions, does your child's opinion count?" 20% of respondent said "No" or "Irrelevant". This is a startling statistic demonstrating the extent to which children with impairments can be marginalised within their own home, either because they are not worthy of an opinion, or because that are unable to communicate adequately (the latter largely accounts for the "irrelevant response".

FIGURE 21: IN FAMILY DISCUSSIONS, DOES YOUR CHILD'S OPINION COUNT?



Anticipated Stigma

There is a high level of stigma associated with the anticipation of a cause of effect which prevents children and youth with impairments from being fully included within their family and community. Anticipated stigma is much to blame for the prevalence of children with impairments being kept indoors, and away from other people. The following statistics provide a snapshot of the feedback provided during our stigma survey:

- 10.5% of people told us they would prefer that people didn't know about their child impairment
- 16.1% of people told us their child would cause social problems for their family in the community
- 27.8% felt that their child's difficulties would cause them to have problems in getting married

Self-Stigma

Self-Stigma can affect both people with impairments as well as their families. Below shows an indication of how self-stigma has affected the parents and families of those children identified with impairment.

- 13% said they thought their neighbours and others in their community think less of their family because of their child's impairment.
- 8.4% said that others have avoided them because of their child's impairment.
- 18.3% thought less of themselves because of their child's impairment and that it has it reduced their pride or self-respect.

Further, the following statistics could offer a reflection of outcomes caused by self-stigma of children with impairments:

- 16.6% of parents reported that their child was not comfortable meeting new people.
- 20.2% parents reported that their child did not have friends as many other children do.

4. Conclusion

The community mapping study for children with disabilities was very necessary not only to obtain accurate information to the EEE project team but also to inform other organizations whose mission is to protect and assist vulnerable children to ensure their lives are fulfilled and their rights upheld, but and also to inform decision makers at both district and national levels.

These community mapping findings will enable FCYF and its partner Jubilee Action to understand its target group across Musanze district so that intervention strategies are formulated accordingly. The results of the assessment revealed that most of the disabled children were born with disability while for others it was due to sickness and few disabilities resulted from other factors like accidents, war, etc. The majority of children with disabilities (i.e. 80%) stated that they are studying while 20% said that they do not go to school though the majority of them confirmed that there is nearby school.

It was noticed during the analysis of findings that in Musanze district, the three most common types of impairments were physical, speech and hearing impairments. Though FCYF has established a Deaf school in the district, it requires greater capacity to support more children with speech and hearing impairments as 810 children were found to have hearing impairment and communication difficulties.

Regarding the identification of stigma for the children with disabilities, it was found that nearly 62% said that there is no stigma while 20% agreed and approximately 18% thought otherwise (sometimes, irrelevant, etc).

Due to the difficulty in communicating with children who have communication impairments, there are limitations to understanding the true extent of the discrimination felt towards these children and that stigma which stands in their way must be addressed from the root causes. In some cases, addressing discrimination against children with disabilities requires working towards the provision of services that meet their special needs. This includes early detection and intervention in health, and specialized education for children with intellectual or sensory disabilities. Efforts to address discrimination against children with disabilities at community level will also have the positive effect of preventing the development of discriminatory attitudes towards those with disabilities in subsequent generations.

5. Limitations to the data

During a critical review of the mapping process in Musanze district, we have identified the following limitations to our data which must be noted before utilising the data within this report.

Firstly, a number of the questions asked to the respondents were too ambiguous. For example, respondents were asked "do you have a nearby school?" The answer to this was open to interpretation as people with physical impairments may consider 'nearby' as different to those with physical impairments. During the next mapping stage we will instead ask respondents to estimate both the distance and the time it takes to arrive at the nearest school to their home.

Secondly, our percentage data is based on a sample of 80% of children and youth (aged 3-25) with hearing impairments and a 40% sample of children and youth (aged 3-25) with other impairments. However, no person was turned away if they wanted to complete a questionnaire and this resulted in a very small number of people over 25 completing the questionnaire. In the future mapping exercises we will ensure that our data for these two groups is disaggregated to gain even more accurate information about our target group for the EEE project.

Thirdly, our data captures the number of people with multiple impairments but our analysis has not allowed us to understand any trends in combinations of impairments experienced by individuals. We will implement a better coding system to ensure that it is possible to analyse this in the further mapping studies undertaken by the EEE project.

Fourthly, the original purpose of this mapping study was to map those children with hearing and communication impairments. However, the NCPD requested that the EEE project also noted all people with impairments. The expertise afforded to the project was that of audiology and speech and language therapy, specific to assessing the original target group. The team expanded their mapping to include all disabilities; however the training for the team on identifying all disabilities was limited.

Fifth, when collecting information about stigma faced by children and youth, it was most common that their parents were asked to answer on behalf of their children, especially where children faced difficulties in communication because of their impairment. This has resulted in data which is not entirely representative of the views of the most vulnerable. Factors influencing these findings included pride and embarrassment felt on behalf of the parents. For future mapping studies, EEE would like to develop some pictures to represent attitudes and feelings so that children can also contribute more actively to this survey of stigma.

Lastly, we must note that the EEE team undertook this mapping study with limited resources and within a timeframe of five months. Those members of the community who were note reached during the community visits are continuing to contact the project and their information is added to the data set. This report was published in November 2013. For more details on the latest information in Musanze district, please email Elie Ndwayesu: endwayesu@hotmail.com .

6. Recommendations

- In future mapping exercises, the EEE data collectors should be reduced in number and provided with a longer period of training prior to field work in order to improve data quality. A process of data validation must also be undertaken over the first month of data collection to ensure the effectiveness of the questionnaires in gathering appropriate responses.
- The community mapping study should be duplicated in all districts of Rwanda to enable decision makers and other development partners to come up with intervention strategies which are evidence-based;
- The Ministry of Education should develop strategies ensuring that more deaf schools are put in place at sector level and tutors/peers for children with disability are coached;
- Since the large proportion of the disabled children in the district have physical impairments, wheel chairs and prosthetic services should be provided for those who are in need. Therefore, some causes of disability would be dealt with while others could be difficult since they are congenital.
- Vocational schools are paramount to enable disabled children to acquire skills which would help them to generate income;
- The fact that most of the parents of children with disabilities are not literate, sensitizations should be conducted at cell and village level so that awareness about children rights is raised and thus child abuse especially for the most vulnerable children is reduced and avoided.
- Given that the person in charge of social affairs at sector level has many tasks/responsibilities, there should be someone in charge of child protection as well as ensuring that the most vulnerable and disabled children and youth are catered for.
- Trainings on child rights should be conducted from the district up to the village level to improve protection of children from violence, abuse, exploitation and discrimination.

ANNEXES

ANNEX 1: Questionnaire for identification of children with disability at Village level

EDUCATION EQUITY AND EMPOWERMENT PROJECT (EEE)

URUTONDE RW'ABANTU BAFITE UBUMUGA /LIST OF PEOPLE WITH DISABILITY

MU MURENGE WA/ SECTOR ……AKAGARI KA/ CELL……..umuduguduwa/village……

Name	Gender	Father's Name	Mother's Name	Age	Impairments	Education	Certificate	Job	Village
1									
2									
3									
4									
5									
6									
7									
8									
9									
10									
11									
12									
13									
14									
15									
16									

Legend

PI: physical Impairment

SI: Speech Impairment

HI: Hearing Impairment

II: Intellectual Impairment

VI: Vision Impairment

OI: other Impairment

ANNEX 2: Assessment Questionnaire

FAIR CHILDREN/YOUTH FOUNDATION (FCYF)/ EEE PROJECT/ ASSESSMENT FORM

IFISHI Y'ABANA N'URUBYIRUKO BAFITE UBUMUGA BARI HAGATI Y'IMYAKA (3 -25)

I. UMWIRONDORO/PERSONAL DETAILS

AMAZINA/NAME: ……

ITARIKI Y'AMAVUKO/ DATE OF BIRTH: ……. / …… /……

AHO YAVUKIYE/ PLACE OF BIRTH:

1. Intara/Province: ……..
2. Akarere/District: …….
3. Umurenge/Sector: ……
4. Akagari/Cell: ……
5. Umudugudu/Village ……

IGITSINA: Gabo/Male ☐ Gore/Female ☐

I. **A. ABABYEYI/ PARENTS:**

1. Se/Father ……..
2. Nyina/ Mother: ……
3. Umurera/Care takers: ……

I. **B. IRANGAMIMERERE/MARITAL STATUS:**

1. Ingaragu/Single : ☐
2. Arubatse/Married : ☐

3. Umupfakazi/Widow(er) : ☐

4. Baratandukanye/Divorced : ☐

I. **C. AMASHURI YIZE/EDUCATION BACKGROUND:**

1. Ntiyize/none: yego/yes ☐

   Oya/no ☐

2. Yarize/studied yego/yes ☐

   Oya/no ☐

3. Ariga/studying yego/yes ☐

   Oya/no ☐

4. Niba ari yego yigahe? /if yes, where? ……

5. Abanza/Primary ☐

6. Ayisumbuye/Secondary ☐

7. Kaminuza/University ☐

8. Imyuga/Vocational skills ☐

Hari ishuri ribegereye is there any nearest school? yego/yes ☐ Oya/no ☐

Niba ari yeho Ryitwa gute? If yes state the name of the nearest school……

ICYO AKORA/OCCUPATION: ……

II. **AMAKURU KU BIJYANYE N'UBUMUGA/INFORMATION ON IMPAIRMENT**

A) UBWOKO BW'UBUMUGA/ TYPE OF IMPAIRMENT

☐

1. Ubumuga bw'ingingo/ physical Impairment ☐
2. Ubumuga bwo kutavuga/ Speech Impairment ☐
3. Ubumuga bwo kutumva/ Hearing Impairment
4. Ubumuga bwo mumutwe/ Intellectual Impairment ☐
5. Ubumuga bwo kutabona/ Vision Impairment ☐
6. Ubundi bumuga OI: other Impairmen ☐

B) **ICYATEYE UBUMUGA/CAUSE(S) OF IMPAIRMENT**

1. Yarabuvukanye/ Born with: ☐
2. Uburwayi/Sickness: ☐
3. Impanuka/ Accident: ☐
4. Intambara/ War: ☐
5. Genocide : ☐
6. Indi mpamvu/ other: ☐ Yigaragaze/ Specify: …….

C) IGIHE AMARANYE UBUMUGA/ TIME SPENT WITH IMPAIRMENT

……

……

……

AMAKURU KU BIJYANYE N'UBUFASHA/INFORMATION ABOUT ASSISTANCE

A)**UBUFASHA YAHAWE/ PREVIOUS ASSISTANCE:**

Yego/yes ☐ Oya/no: ☐

Niba ari yego ni ubuhe?/ if yes Specify …….

B)**NINDE WATANZE UBWO BUFASHA/ WHO IS THE PROVIDER**

1. Ubuyobozi bwa leta/government ☐
2. Umuryango uteri uwa leta/ non-government organization ☐
3. Umushinga/Project ☐
4. Itorero/church ☐
5. Umuntu kugiti cye/ individual ☐

C) ICYO UBUFASHA BWAMARIYE UWABUHAWE/THE IMPACT OF THE ASSISTANCE PROVIDED

……

……

……

D) UKO UMUGENERWA BIKORWA YIYUMVA/ BENEFICIARY'S EMOTIONAL FEELINGS.

……

……

III. IMIBEREHO Y'UMURYANGO W'UMUGENERWA BIKORWA/ BENEFICIARY'S FAMILY BACK GROUND AND SOCIO-ECONOMIC SITUATION:

A) AMASHURI ABABYEYI BIZE/ PARENTS' EDUCATION BACK GROUND:

1. Se/Father: ……

2. Nyina /Mother: ……

B) **IMITERERE Y'UMURYANGO/ FAMILY SITUATION:**

Se akora iki/Father's occupation: …….

Nyina akora iki /Mother's occupation: ……..

Umubare w'abana/size of the family ……

Bafite isambu/do they have land? Yego/ Yes: ☐ ya/ No: ☐

Bafite inzu yo kubamo/do they have a house? Yego/ Yes: ☐ No: ☐

Bafite itungo/do they a have domestic animal? Yego/ Yes: ☐ No: ☐

Niba ari yego irihe?/if yes specify……

Icyicyiro cy'ubudehe /family category 1 2 3 4 5

C) AMAHUGURWA ABABYEYI BABONYE KU BIJYANYE N'UBURENGANZIRA BW'UMWANA /PARENTS' KNOWLEDGE ABOUT CHILD RIGHTS:

……

……

D) ICYO ABABYEYI BATEKEREZA KU MYIGIRE Y'ABANA BAFITE UBUMUGA MURI RUSANGE/ WHAT PARENTS THINK ABOUT INCLUSIVE EDUCATION:

……

……

IV. ICYITONDERWA/ OBSERVATION

……

……

Nemeje aya makuru ntanze ashobora gukoreshwa mubushakashatsi

Italiki/ Date: ……./……/……

Umukono, amazina y'uwujuje fishi/ For staff

……

Umukono wa nyirifishi/

Signature of Beneficiary

.....

ANNEX 3: Stigma Questionnaire

STIGMA IDENTIFICATION

	Tick					Circle				Add score circled
Impact - Partipation Scale*	Not answered	Yes	Sometimes	No	Irrelevant	No problem	Small	Medium	Large	Score
Wibwira ko umwana wawe afite amahirwe angana n'ayabandi bana yo kujya kw'ishuri?Does your child have an equal opportunity to go to school as other children?										
Niba ari rimwe na rimwe cyangwa oya wumva icyo kibazo gikomeye bingana iki? [if sometimes or no] How big a problem is it to you?						1	2	3	5	
Umwana wawe yitabira iminsi mikuru y'umuryango/cyangwa indi minsi mikuru isanzwe nk'amakwe ibiriyo n'ibindi? Does your child take part in major family /community festivals and rituals as other children do? (e.g. weddings, funerals, religious festivals)										
Niba ari rimwe na rimwe cyangwa oya wumva icyo kibazo gikomeye bingana iki? [if sometimes or no] How big a problem is it to you?						1	2	3	5	
Umwana wawe akunze kujya gusenga kimwe n'abandi bana bose?Does your child attend and participate in church as often as other children?										
Niba ari rimwe na rimwe cyangwa oya wumva icyo kibazo gikomeye bingana iki? [if sometimes or no] How big a problem is it to you?						1	2	3	5	
Umwana wawe akunze gusura abaturanyi muri rusange kimwe nk'abandi bana bose?Does your child visit other people in the community as often as other children do?										
Niba ari rimwe na rimwe cyangwa oya wumva icyo kibazo gikomeye bingana iki? [if sometimes or no] How big a problem is it to you?						1	2	3	5	
Umwana wawe agira umwanya wo gukina imikino ngorarangingo cyangwa indi mikino kimwe nabandi bana ? Does your child take as much part in sports or other recreational activities as often as other children do?										
Niba ari rimwe na rimwe ycangwa oya wumva icyo kibazo gikomeye bingana iki? [if sometimes or no] How big a problem is it to you?						1	2	3	5	
Umwana wawe akunze kugenda munzu cyangwa hanze yayo mu baturanyi no mu mudugudu nkuko abandi babikora?Does your child										

move around inside and outside the house and around the village / neighbourhood just as other people do?										
Niba ari rimwe na rimwe cyangwa oya wumva icyo kibazo gikomeye bingana iki? [if sometimes or no] How big a problem is it to you?						1	2	3	5	
Mu biganiro byo mu muryango ibitekerezo by'umwana wawe bihabwa agaciro?In family discussions, does your child's opinion count?										
Niba ari rimwe na rimwe cangwa oya wumva icyo kibazo gikomeye bingana iki? [if sometimes or no] How big a problem is it to you?						1	2	3	5	
Umwana wawe yumva amerewe neza iyo ahuye n'abantu bashya?Is your child comfortable meeting new people?										
Niba ari rimwe na rimwe cyangwa oya wumva icyo kibazo gikomeye bingana iki? [if sometimes or no] How big a problem is it to you?						1	2	3	5	
Umwana wawe agira inshuti nyinshi nk'uko abandi bana bakunze kuzigira? Does your child have as many friends as other children do?										
Niba ari rimwe na rimwe cyangwa oya wumva icyo kibazo gikomeye bingana iki? [if sometimes or no] How big a problem is it to you?						1	2	3	5	
TOTAL										

ANTICIPATED STIGMA

Circle the answers

Anticipated Stigma	Yego/Yes	yaba byashoboka Possibly/	Ntabwo mbyizeye Uncertain	Oya No	score
Bigushobokeye wakwifuzako abantu batamenya ko ufite umwana ufite ibibazo? If possible, would you prefer to keep people from knowing about your child difficulties?	4	3	2	1	
Wumva ko ikibazo cy'umwana wawe cyateye umuryango wawe ibibazo mubandi baturanyi? Do you feel that your child problem has caused social problems for your family in the community?	4	3	2	1	
Wumva ko ibyo bibazo bizatuma umwana wawe atazarongora? Do you feel that these difficulties will cause your child problems in getting married?(Unmarried only)	4	3	2	1	
Wumva ucishijwe bugufi kubera iki kibazo? Byaba byaragabanyije agaciro ufite cangwa bituma usa n'utiyubashe? Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?	4	3	2	1	
Wibwirako abaturanyi bawe batubaha umuryango wawe kubera iki kibazo?Do you think your neighbours and others in your community think less of your family because of this problem?	4	3	2	1	
Wibwira ko abandi batakwegera kubera iki kibazo?Do you feel others have avoided you because of this problem?	4	3	2	1	
Wibwira ko iki kibazo cyatuma n'undi wo mumuryango wawe atarongora?Do you feel that your problem make it difficult for someone else in your family to marry?	4	3	2	1	
Total					

ANNEX 4: FAMILY CATEGORIES

The program categorized Rwandans in six categories depending on the economic status of each individual household, these are:

1) Those in **abject poverty** locally referred to as 'abatindi nyakuja', own no property, live on begging and help from others, and consider it lucky if they died.
2) The second category, is the **very poor** and these have no house, live on poor diet which they can afford with difficulty, work every day for others for their survival, have tattered clothes, own no portion of land, and do not own cattle.
3) The third category is called the **poor**. These depend on food deficit in nutrients, own a small portion of land, have low production and their children cannot afford secondary education.
4) The fourth category comprises the **resourceful poor** who own some land, cattle, a bicycle, have average production, their children can afford secondary education, and have less difficulties in accessing health care.
5) In the fifth category lie the **food rich people** who basically own big lands, eat balanced food diets and live decent houses. They employ others, own cattle, and their children easily afford university education.
6) The sixth category is the **money rich**, who comprise of people with money in banks, receive bank loans, own a beautiful house, a car, cattle, fertile lands, sufficient food and are permanent employers.