

MUREKE DUSOME

**Needs Assessment for Children with Disabilities to Return to
or Start School**

INTRODUCTION

Through community literacy interventions, the USAID-funded Mureke Dusome activity has fostered a culture of reading among girls and boys, with and without disabilities. In collaboration with the Ministry of Education, Mureke Dusome increased access to high quality, age-appropriate, relevant reading materials in the community and engendered ownership at the national and local levels to sustain activity interventions.

Gender and inclusion are integrated throughout Mureke Dusome's activities. Mureke Dusome has established reading clubs per school catchment area across the country in an effort to increase community and parental involvement to improve literacy skills for children in Grade 1-3, including children with disabilities. In 2019/2020, Mureke Dusome initiated partnerships with the National Council of Persons with Disabilities (NCPD) and a local organization, Uwezo Youth Empowerment, which specializes in inclusion to work together in supporting literacy for children with disabilities. By the end of October 2020, Mureke Dusome, in collaboration with Uwezo, identified more than 3,274 children with disabilities from 0 to 13 years in the 5 model districts of Burera, Kirehe, Ruhango, Gasabo and Ngororero. The purpose of this activity was to help children with disabilities to increase their full participation in community literacy activities and to advocate for their rights in general. Of the 2,272 children with disabilities aged 7 years and over who were identified, only 61.2% of school age children with disabilities were in school before the onset of the pandemic; 38.8% had either dropped out or had never been enrolled in school before schools were closed due to the COVID-19 pandemic.

Starting in July 2020, Mureke Dusome trained parents of identified children with disabilities through a series of monthly workshops and home visits on how to support their children's reading and learning at home. At the end of every workshop, every parent borrowed a storybook with inclusion messages to read with or for their child at home before the following workshop. Parents were encouraged to use stories from these storybooks to teach their children and also to come up with stories of their own that can inspire their children to learn new words and skills and to help them know that they are capable and loved.

Mureke Dusome also trained 715 Community Education Workers (CEWs) and kick-started working relationships between CEWs with 137 Youth Volunteers with Disabilities (YVDs) in September and October 2020. These trainings were designed to equip both CEWs and YVDs with the knowledge and skills needed to accommodate children with disabilities in community reading activities. In addition, this training was intended to enable them to build the capacity of others in the community, including caregivers of children with disabilities, with the knowledge and basic tools to address functional challenges and external factors that influence learning for children with various physical, sensory and learning difficulties. During the training, YVDs shared individualized cases of children with disabilities in their respective cells and developed action plans together with CEWs on how best to accommodate them in community reading activities based on individual children's identified needs. In addition, YVDs conducted home visits to families of children with disabilities to monitor how parents practice with their children what they learn in the workshops, including the practice of reading books with children.

Considering that in previous years, few children (less than 1%) who attended reading clubs were children with disabilities, Mureke Dusome conducted a needs assessment to better understand their needs so that they can all start or go back to school when schools reopen and to also ensure that the right accommodations are in place for them to participate in reading activities in the community and at home. The needs assessment was designed to help identify children with disabilities who need assistive devices and/or scholastic materials for returning to schools or starting school (for those who have not yet enrolled).

METHOD AND PARTICIPANTS

Data Collection

The needs assessment was conducted by the 137 trained Youth Volunteers with Disabilities (YVDs) (two per sector) and 5 YVDs coordinators in 66 sectors of Ngororero, Ruhango, Burera, Gasabo and Kirehe districts. They received a one-day training from Mureke Dusome staff on how to safely collect data and ensure confidentiality as well as data quality. They used a structured survey questionnaire in collecting data, and the data collection took place over the course of ten days from 16th to 27th November 2020. The questionnaires were completed based on conversations YVDs had with parents or caregivers of children with disabilities. The data was collected during home visits and phone calls. In cases where households were located in areas where the YVDs could not reach due to environmental factors or assessment timelines, families were reached by phone. All data collection was done while respecting COVID-19 prevention measures.

The data collection tool has been programmed in a web-based platform called KoBo toolbox ([Click here to view the tool](#)) to allow smooth, quick and timely data entry and data analysis.

Participants

Respondents were selected based on the pre-determined characteristics shown from the mapping of children with disabilities that was conducted by Mureke Dusome in five model districts before the needs assessment, including but not limited to: children with disabilities who are in the school-age range for grades P1 to P3, either enrolled or not in schools from the five pilot districts. All identified children with disabilities in mapping activities were reached during the assessment through their parents.

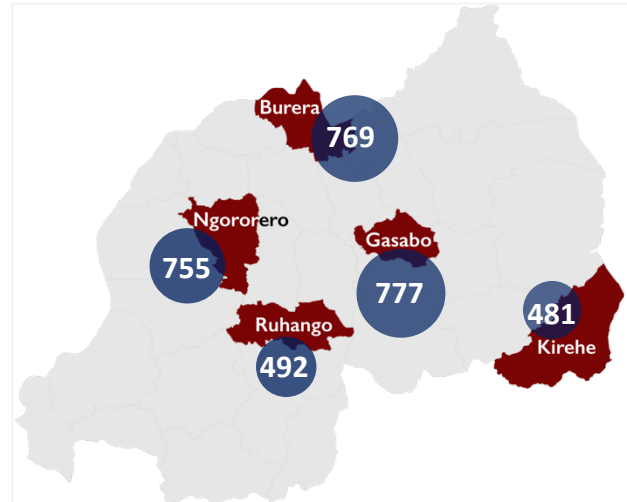
FINDINGS

During data collection, the assessment field teams (YVDs) spoke with parents and caregivers of children with disabilities, and asked about the different needs of their children. The participation of parents as well as that of children in this assessment was essential to gain a comprehensive understanding of each child's identification, demographic characteristics, and their location. The findings revealed that 3,274 children from five pilot districts have different types of disabilities, 69% of them aged seven and above, have different needs to be able to go back to school including, assistive devices (20%), scholastic materials (54%) and treatment (8%).



As the above diagram indicates, more than half of children with disabilities identified are boys (56.6%) and 43.4% are girls.

The map on the right shows the distribution of identified children with disabilities per district, where Gasabo, Burera, and Ngororero districts each have at least one-fifth of the children reached during the assessment, while 15% and 14.7% are from Ruhanga and Kirehe districts respectively.



Map: Distributions of identified children with disability by district

Mureke Dusome has been implementing different inclusion activities including (1) awareness workshops with parents of children with disabilities, (2) airing inclusion PSAs on radio and TV, (3) distributing Kinyarwanda storybooks with inclusion messages and (4) advocating for children with disabilities. This has improved parents' mindset so that they feel more comfortable removing their children from hiding and advocating for them as much as they can; this resulted in an increase in the number of children with disabilities identified during the needs assessment as compared to the initial identification exercise. The assessment has shown that a large number of children with disabilities across all five districts are boys (59.7% in Burera 59.7% in Kirehe, 56.3% in Ruhanga, 55.5% in Ngororero, and 52.8% in Gasabo), but the results do not explain this difference. Having a child with a disability is a source of shame, and it is possible that many families of girls with disabilities hide them from public view. This gender disparity is likely a result of underreporting due to stigmatization of multiple and intersectional identities. For girls with disabilities, gender and age are additional sources of disadvantage because of the subordinate location of girls in social relations. But further assessment and analysis is required to explain this disparity and the implications for policy and interventions targeting children with disabilities¹.

¹ For more on gender disaggregation of children with disabilities by district refer to appendix I.

Age distribution among identified children with disabilities

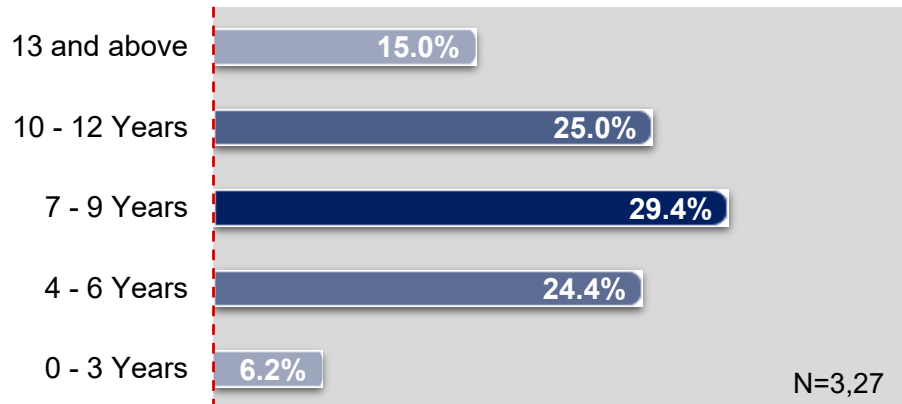


Figure 1: Distribution of identified children with disability by their age

As shown in the graph above, although the project targets children aged between 7 to 9 years, in grade 1 to 3 (whether enrolled or not), the needs assessment gathered information on the needs of children with disabilities from different age ranges. This needs assessment considered children from ages 0 to 18 (given that they are in primary grade 1-3) because a lot of children with disabilities start school late or often repeat classes. Another reason is that a large sample size would be easier for long term advocacy and to identify trends of types of support that would be likely to be needed over time, to support the sustainability of future initiatives. For example, knowing which percentage of children in the 4-6 age range who have disabilities allows for advocacy with the government to ensure that they are preparing the needed assistive devices and scholastic materials for these children before they enter Primary I, and it allows for giving a sense of how there are similar numbers of children with disabilities across the different age ranges.

School enrolment

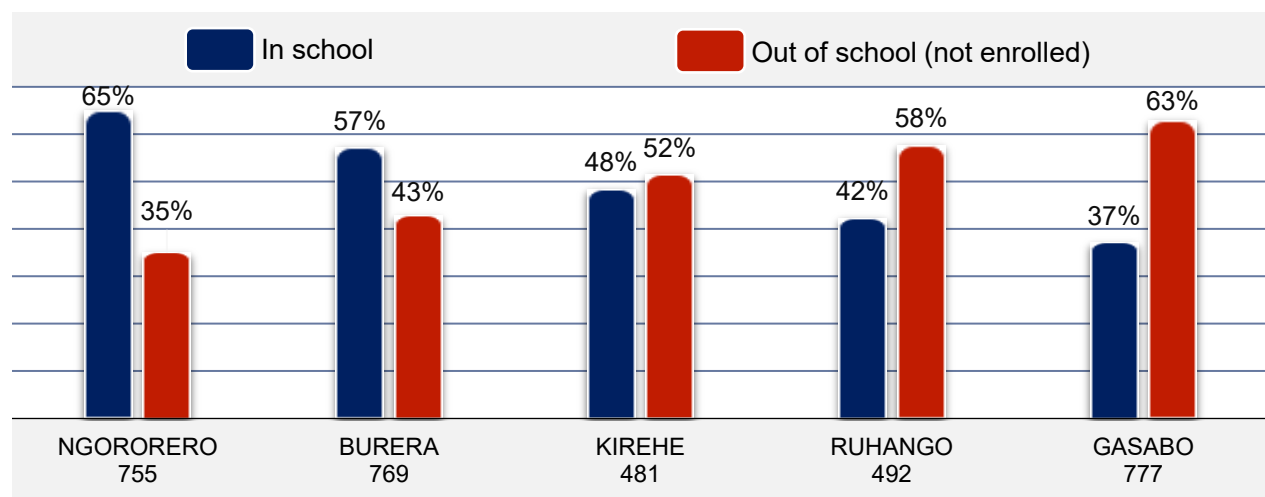


Figure 2: School enrolment of identified CWDs by district

The assessment revealed that on average more than a half, which means 5 in 10 children with disabilities (50.7%) reached in the 5 districts, were already enrolled in school either in nursey, primary or secondary. While only 61.2% of 2,272 children aged 7 and above (who are eligible to start school) are enrolled in school in grades 1 to 6. The above graph indicates that the district of Ngororero has more than the other

districts of children enrolled, with nearly two-thirds of the children with disabilities (65%) who are in school, followed by Burera with more than half (57%). The finding shows that 63% of children with disabilities in Gasabo, 58% in Ruhango, and 52% in Kirehe districts are not studying in schools.

Of the 1,237 (43.8%) out of school children with disabilities, 12% (151) had dropped out of school due to various reasons while 55% (676) are not planning to start school and 33% (410) had never enrolled but are planning to start when schools reopen. Of those who dropped out, some report to plan to return to school in 2021 if the government reopens all schools. At the time of data collection, lower primary schools and nursery schools remained closed due to COVID-19². Unfortunately, a large number 66.8% (827) are not planning to start or go back to school because of the following barriers reported by their parents:

- ✎ Negative attitudes by numerous stakeholders in the community (parents/caregivers, children, teachers, leaders) who do not think children with disabilities can learn. For instance, out of 827 parents whose children are out of school, half of them (52%) reported their children have severe disabilities and are unable to study;
- ✎ Poverty prevents families of children with disabilities from providing basic needs to enable them to go to school. Of the total number of children with disabilities surveyed, 66% (2,114) are from households in category one and two of *Ubudehe* (lowest income categories);
- ✎ Mainstream schools are inaccessible to most children with disabilities while special schools for children with disabilities are far away and too expensive;
- ✎ Children need reasonable accommodations before they can start schooling;
- ✎ Fear of stigma and shame of having a disability.

Type of disability

The graph below shows that, out of 3,274 children with disabilities, the majority of disabilities reported were physical or sensory, where 42.5% of children have physical disabilities, 21.9% have mental disabilities, 20.2% have multiple disabilities, 14.2% have a speech impairment, 5.9% are blind, and 0.8% have albinism. This assessment administered a question to identify children having any type of disability by allowing individuals or parents to self-report the type of disability (ies), but it did not provide definitions for each disability, severity or an assessment of disability. Therefore, a survey should be conducted on parent/caregiver attitudes towards disability to provide more insight on the stereotypes that still exist that may prevent stakeholders from self-reporting.

²The Ministry of Education announced that lower primary and pre-primary schools will reopen on January 18, 2021.

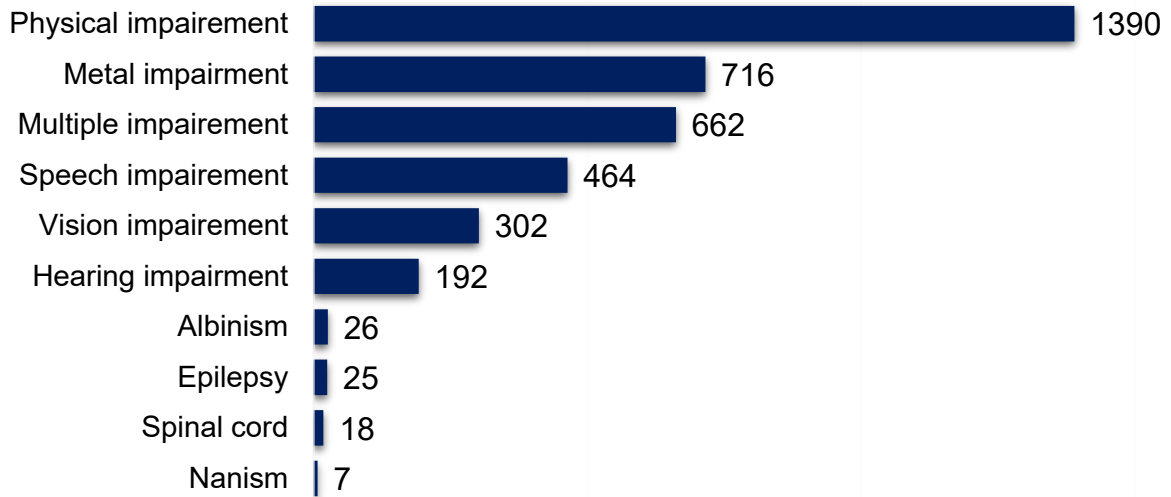


Figure 3: Distribution of identified children with disability by type of disability

Children with disabilities with assistive devices and treatment needs

Through the needs assessment, Mureke Dusome aimed to identify which assistive devices and scholastic materials are needed for children with disabilities to go back to or start school. This is why parents were asked if their children have been formally diagnosed to have any impairment that hinders their children from going to school. The findings indicate that more than three-fifths of all 3,274 children with disabilities (64%) have been formally diagnosed by a doctor to have disabilities. During data collection, 51% (1,655) showed a copy of the details of the assistive devices and treatment that were prescribed or a disability card. The graph below shows medication and type of assistive devices prescribed by a doctor:

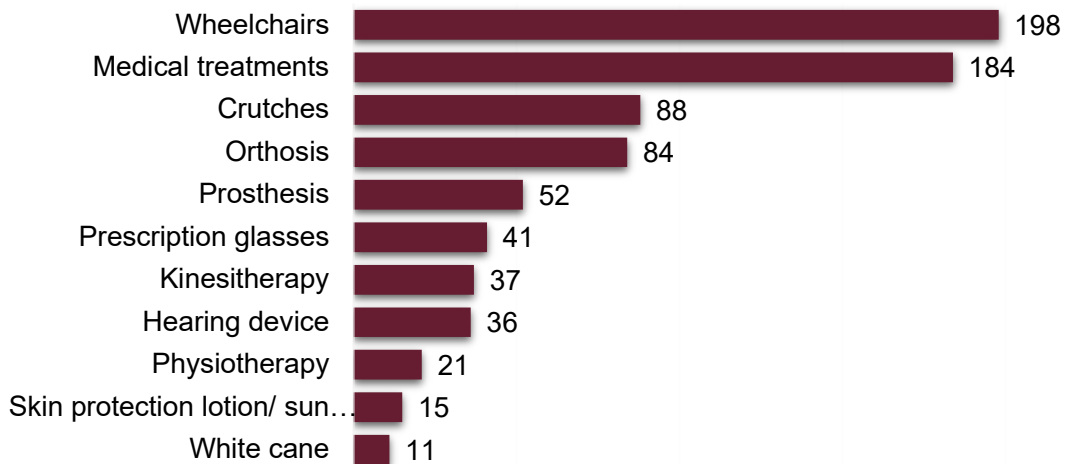


Figure 4: Medication and type of assistive devices prescribed by a doctor

According to a large number of children with disabilities who report to having physical disabilities, the number of children prescribed by a doctor to use a wheelchair is 198, while 88 need crutches, 84 need orthosis, 52 need prosthesis, 41 need prescription glasses and 36 need hearing devices. Moreover, parents of 184 children with disabilities reported that their children need special medications for a certain period

of time before going to school, and 58 reported needing to go for kinesitherapy and physiotherapy. 36% of all reported children with disabilities have not been formally diagnosed nor been given a disability card by the Government of Rwanda and therefore, this data does not include children who need devices and treatment for the first time. Through parent awareness workshops and home visits, Youth Volunteers with Disabilities informed parents on where and how to get their children diagnosed and treated but more advocacy needs to be done to ensure all children are screened and given treatment and assistance where necessary.

In addition, Mureke Dusome asked parents if their children with disabilities have a prescribed assistive device that may need repairing. 240 parents agreed that their children’s equipment should be repaired because they are too old and damaged. As the graph below indicates, the majority (41%) claim that their wheelchairs need to be repaired, and 16%, 15% and 10% need their crutches, orthosis, or prosthesis to be repaired or renewed respectively. Under 9% wish to have new or repaired glasses, hearing devices, sun cream or white cane. When asked about the damaged devices that need repair or to be replaced, below were the parents’ responses:

- ✗ The crutches used are from childhood and children have grown up so they have to bend their back to use them;
- ✗ The orthosis and prosthesis seemed too small compared to children’s age so they need new size-appropriate devices;
- ✗ The batteries inside the hearing device expired;
- ✗ Glasses which have gone beyond the prescribed lifespan;
- ✗ Wheelchairs’ tires, seating, and other parts have been damaged and worn out;
- ✗ Sunscreen is finished and they cannot afford to buy more.

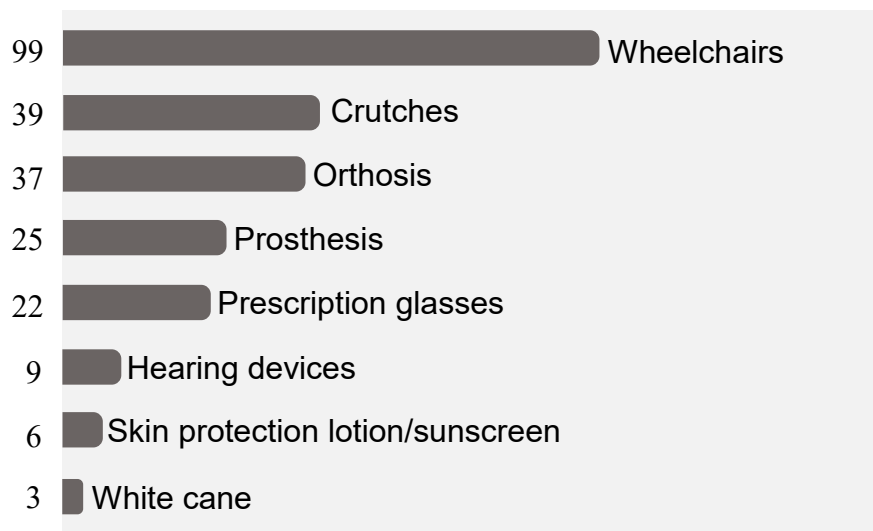


Figure 5: Assistive devices that need repair or replacement

Children with disabilities’ scholastic material needs

During the needs assessment, Mureke Dusome asked the parents of 2,272 children with disabilities about any scholastic materials other than assistive devices that children need to be able to go back or start school. The assessment revealed that the majority (74%) need school uniforms, close to three-fifths (71%),

69%, and 67%) need notebooks, shoes, and school bags respectively and only 39% need school fees so that they can go back or start school.



In addition, the limited access to transportation to schools due to geographical and built environmental barriers at schools, such as classrooms on a higher mountain or inaccessible schools were identified by parents as prevailing barriers that need to be removed in order for children with disabilities to go back or start school.

CONCLUSION

SUMMARY OF FINDINGS

This report presented the findings from an assessment of the needs of children with disabilities to start or go back to school. More than half of 3,274 children with disabilities from 5 districts are enrolled either in nursery or primary school, and of those 2,271 children at the eligible age to start school, only 61.7% were enrolled in primary schools, with almost 40% not enrolled in schools.


As Mureke Dusome previously documented, a large number of children with disabilities across all 5 districts are boys (59.7% in Burera, 59.7% in Kirehe, 56.3% in Ruhango, 55.5% in Ngororero, and 52.8% in Gasabo), signaling that people with multiple marginalized and intersectional identities are subject to stigmatization including underreporting.

Majority of children with disabilities (72%) need school uniforms while more than three-fifths (69%, 68%, and 65%) need notebooks, shoes and school bags respectively. Only 42% need school fees so that they can go back or start school. 240 parents reported that their children's assistive devices should be repaired or replaced because they are too old, damaged and/or no longer appropriate for the child's size

Findings indicate that more than 64% of children with disabilities have been formally diagnosed by doctors to have disabilities, and 51% (1,655) have shown a copy of the details of the assistive devices and treatment that was prescribed and/or a disability card. This means that 36% of children with disabilities have not been diagnosed, making it more challenging to secure the assistive devices and support they need.

The assessment also revealed that out of 924 parents whose children are out of school, half of them (52%) reported that their children have severe disabilities and are unable to learn.

RECOMMENDATIONS

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 A concerted effort needs to be made at all levels toward child with disabilities identification, recruitment and retention for school attendance. Advocacy should be done at all levels to ensure all stakeholders in the community (locally, nationally and regionally) so that children with disabilities are supported to go to school. In addition, Mureke Dusome and other educational stakeholders should continue to support these children in terms of financial support to pay school fees, give them school materials, provide assistive devices, ensure that all schools are accessible

by examining the distance to schools and infrastructure, training parents on how they can use Income Generating Activities to overcome poverty etc.. More sustainable approaches would also include be investing in social protection schemes by the Government of Rwanda including regular cash transfers that can be accessed by households of children/persons with disabilities to increase the likelihood of children getting access to quality education.

- ✎ Mureke Dusome should continue to partner with like-minded institutions interested in promoting inclusion in Rwanda, and to advocate with MINEDUC and REB to enable the provision of improved services for these children. Local government officials and NCPD can work with community volunteers to mobilize parents/caregivers and children with disabilities that are not attending school to visit school programs that are successfully serving students with disabilities and to see in person the achievements students with disabilities are reaching.
- ✎ Navigating referral procedures and applications for social support can be a daunting experience for parents. Many parents have reported that their children with disabilities do not have a disability card which limits the services and supports they get from the Government of Rwanda including medical care. So, there should be trained volunteers with disabilities or civil servants who can assist parents to get access to Government social protection schemes.
- ✎ A fundamental shift in negative attitudes towards children with disabilities that undermine their capabilities will require building the awareness and capacity among all community members including teachers, children, parents/caregivers, village leaders and various policy makers around issues on disability. SBCC messages should explicitly address the widespread misconception that disability, age and gender equate to deficiency and should challenge disabling social norms and negative stereotypes about persons with disabilities through inclusion of girls and boys, men and women with disabilities as leading voices in program activities.
- ✎ There is need for more initiatives (in and out of school) to undertake assessments to understand the situation of children with disabilities and to take specific steps to promote their full inclusion in society. Furthermore, in-depth assessment and gender sensitive analysis should be conducted, in particular to further examine the reason for gender disparity and its implications for policy and other interventions targeting children with disabilities so that both girls and boys with disabilities are supported to attend schools.
- ✎ There is a need for more advocacy to ensure that all children are diagnosed and supported to get treatment so that they can be able to go to school. Additional support should be given to NCPD to strengthen the current disability categorization process so that screening, referral and specialist support can be undertaken on an in-demand basis. Furthermore, doctors/ clinics and community centers should be provided with additional information and training on the importance of early identification of children with disabilities and the programs and services that are available to support their learning in the community.
- ✎ Generally, there is lack of quality data on children with disabilities that impacts Mureke Dusome's ability to plan and develop inclusive literacy activities and how to accommodate children with disabilities. Currently there is no database that tracks and analyses the number of children with disabilities enrolled in school, their dropout rates nor how to assess the extent to which children with disabilities are missing out on school. The Ministry of Education should be supported and/or form close collaboration with the National Institute of Statistics (NISR) to develop a reliable system to generate comprehensive data which can inform and guide evidence-based strategies to ensure that children with disabilities are enrolled and supported to stay in school.
- ✎ The Government of Rwanda should build a disability sensitive social protection system which includes disability benefits to enable household of children with disabilities to live in dignity and security.

Appendix 1. Gender disaggregation of children with disabilities by district

District	Sex of children with disabilities		Total
	Female	Male	
BURERA	310	459	769
GASABO	367	410	777
KIREHE	194	287	481
NGORORERO	336	419	755
RUHANGO	215	277	492
Total	1,422	1,852	3,274

Appendix 2. Distribution of children with disabilities by type and districts

District	Vision impairment	Speech impairment	Hearing impairment	Physical impairment	Mental impairment	Multiple impairments
BURERA	65	88	39	346	154	119
GASABO	55	122	44	316	174	183
KIREHE	29	79	29	195	139	95
NGORORERO	108	97	44	327	139	150
RUHANGO	35	70	28	192	104	115
Total	292	456	184	1,376	710	662

Appendix 3: Need assessment for children with disabilities to go back or start school

Province: _____ District: _____
 Sector: _____ Cell: _____
 Village: _____ Date (date/month/year): _____

Purpose:

This form is used to identify children with disabilities who need assistive devices and scholastic materials in order to go back or start school. Youth Volunteers with Disabilities will complete this form based on conversations they will have with parents or caregivers of children with disabilities, observations made through home visits and workshops with parents.

Instructions for administering the identification form:

Before filling the form:

- Request for permission to both caregivers and children to ask them the information on the form,
- Explain clearly the purpose of the data collection,
- Avoid giving false expectations to the caregivers and the children,
- Don't give any promise (same as above),
- Record all the answered as provided by the respondents.

Caregiver's and Children identification

Father's names: _____ Contact: _____
 Mother's names: _____ Contact: _____
 Caregiver's names _____
 Child's names: _____ Sex _____ Age _____
 Ubudehe category _____

Household head (specify if it's a single parent, child headed, other family members such as aunt, uncle, grandparents):

No.	QUESTIONS	ANSWERS
1	Is the child enrolled in school? (Yes/No)	Yes: - Already studying (enrolled) - Starting this year - Back to school (if dropped out) 0. No (if no, go to question no. 4)
2	If yes, in which grade level?	
3	If yes, which school?	(Name of school, district and sector)
4	If not enrolled, why?	
5	Type of disability	1. Vision impairment 2. Speech impairment 3. Hearing impairment 4. Physical impairment 5. Mental impairment 6. Multiple impairment 7. Other (specify)
6	Has there been formal/clinical diagnosis performed on the child?	1. Yes 0. No
6a	If yes, do you have a copy of the details of the assistive device that was prescribed? If not, why?	1, Yes 0. No
6b	If yes, was the child prescribed any treatment and/or assistive devices?	1. Yes 0. No
6c	What type of treatment and/or assistive device was prescribed?	1. Wheelchair 2. Crutches 3. Prosthesis

		<ul style="list-style-type: none"> 4. Orthosis 5. Hearing device 6. White cane 7. Prescription glasses 8. Skin protection lotion/sunscreen 9. Other (specify),
7	What else (other than assistive devices) does the child need to be able to go back or to start school?	<ul style="list-style-type: none"> Scholastic materials (specify) <ul style="list-style-type: none"> 1. Notebooks/pens 2. Uniform 3. School bags 4. School shoes 5. School fees 6. Others (specify)
8	Does the child have any assistive device that perhaps needs repairing?	<p>Yes No</p>
8a	<p>If yes, what kind of device is it?</p> <p>What is the damage that needs repair?</p>	<ul style="list-style-type: none"> 1. Wheelchair 2. Crutches 3. Prosthesis 4. Orthosis 5. Hearing device 6. White cane 7. Prescription glasses 8. Skin protection lotion/sunscreen 9. Other (specify),
	Additional comment	

Data collector name: _____

Signature: _____