

Research Report

Formative research on the risk factors and factors contributing to impairments among children and adolescents in Rwanda

June, 2023



Executive Summary

Disability is a major public health concern worldwide and the situation for children and adolescents is even worse. The Fifth Rwanda Population and Housing Census (RPHC) conducted in 2022 reported that 3.4% of the population aged 5 years and above had disability, although the figure is likely below the reality. In fact, the Fourth RPHC (2012) revealed that the prevalence of disability was around 5% and approximately 20% (87,900) of the population of persons with disabilities were children aged between five and eighteen years. Early identification, referral, and management of impairments in children has been emphasized by the National policy of persons with disabilities and its four years' strategic plan (2021-2024). In response to this, different interventions are being carried out within the health sector. However, lack of evidence on disability determinants and factors contributing to the impairment in children constitute a hindrance to the design and success of the above-mentioned interventions. The aim of the reported study was to determine the factors contributing to impairments in children and adolescents in Rwanda, using a mixed method design.

It was found that only 53.3% of mothers of children with disability (CwDs) were living with their spouses legally. The most common identified prenatal factors that may contribute to impairments among children and adolescents were maternal under-nourishment (15.8%), malaria during pregnancy (13.8%), maternal alcohol abuse (12.3%), traditional medicines (10.9%) and bleeding during pregnancy (8.1%). It was reported that 7.7% of the mothers experienced some problems of reaching health facilities during pregnancy and 9.4% of CwDs were born at home. The top reported complications during birth were prolonged labour (36.3%) and asphyxia (24.4%). It was also revealed that 29.9% and 26.4% of the children and adolescents with disabilities had difficulties in feeding and drinking respectively after birth. Regarding the socioeconomic factors, 17% of CwDs' mothers had not attended any school while 64.4% had only attended primary school, and the situation was worse in rural compared to urban areas ($p=0.007$). The results indicated that the majority (66.6%) of CwDs' families were in Ubudehe categories 1 and 2. Furthermore, 73.8% of mothers and 51.9% of fathers of the CwDs had no jobs. Some parents or guardians rarely or never read or tell stories to their CwDs (41.2%), don't sing to them (35.3%), don't do any activity with them (26.7%) or talk to them (16.0%) or play with them (13.8%). While the qualitative results confirmed the quantitative ones, they also revealed factors from the CwDs themselves contributing to impairments and disability such as drug and tobacco abuse.

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Glossary

Impairment: “Any problem in body function or structure as deviation or loss caused by physical, mental or sensory” (WHO, 2002)¹.

Disability: In Rwandan law (N° 01/2007 of 20/01/2007) disability is defined from a medical model and is considered the condition of a person’s impairment of health ability he or she should have been in possession, and consequently leading to deficiency compared to others². According to the World Health Organization (WHO, 2001), disability is defined as an umbrella term of impairment, activity limitation together with participation restriction or loss of opportunities to take part in the normal life of the community on equal level. Disability is a result of the interaction between a person and his or her environment.³

Child and adolescent: The UN Convention on the Rights of the Child (Art.1) defines a child as an individual aged below 18 years and, in time, the United Nation has come to formally define adolescence as the period between 10 and 19 years of age. In this study we also defined a child as an individual aged 0-17, but adolescence as the period between 12 and <18 years of age.

Risk Factors: Health risk factors are attributes, characteristics or exposures that increase the likelihood of a person developing a disease or health disorder.

Contributing factors: are the practices and factors that lead to outbreaks. In an outbreak, contributing factors are the “how” and root causes are the “why”⁴.

Family factors: an element or condition in a family that accounts for a certain disease, disorder, or trait. A familial factor may or may not be inherited⁵.

Biological Factors: Any physical, chemical, genetic, or neurological condition associated with psychological or physical disturbances⁵.

Socioeconomic factors: Socioeconomic factor is the position of an individual or group on the socioeconomic scale, which is determined by a combination of social and economic factors such as income, amount and kind of education, type and prestige of occupation, place of residence⁵.

Environmental factors: The aggregate of external agents or conditions—physical, biological, social, and cultural—that influence the functions of an organism. The physical environment may be measured

1 (WHO, 2022): Towards a Common Language for Functioning, Disability and Health ICF. Retrived from <https://cdn.who.int/media/docs/default-source/classification/icf/icfbeginnersguide.pdf>

2 Rwanda Ministry of Justice (2007). LAW N° 01/2007 OF 20/01/2007 RELATING TO PROTECTION OF DISABLED PERSONS IN GENERAL https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/11/Rwanda_Law-Relating-to-Protection-of-Disabled-Persons-in-General.pdf

³World Health Organisation. (2001). International Classification of Functioning , Disability and Health,. Retrieved from <https://apps.who.int/iris/bitstream/handle/10665/42407/9241545429.pdf?sequence=1>

4 Centers for Disease Cotrol and Prevention. Retrieved from <https://www.cdc.gov/nceh/ehs/nears/what-are-contributing-factors.htm#print>

5Ammerican Pyschological Association (APA). Retrieved from <https://dictionary.apa.org/familial-factor>

in terms of temperature, air pressure, noise, vibration, atmosphere, or sources of nutrients, which in turn may be specified by a range of values⁵.

Abbreviations and Acronyms

CwDs	Children with Disabilities
DH	District Hospital
FGD	Focus Group Discussions
HMIS	Health Management Information System
HI	Humanity and Inclusion
NCDA	National Childhood Development Agency
RBC	Rwanda Biomedical Centre
RNEC	Rwanda National Ethics Committee
RPHC	Rwanda Population and Housing Census
TWG	Technical Working Group
UNCRPD	The United Nation Convention on the Rights of Persons with Disabilities
UNICEF	United Nations Children's Fund
UPHLS	Umbrella of Organizations of Persons with Disabilities in the fight against HIV&AIDS and for Health Promotion
WHO	World Health Organization

I. Introduction

1.1. Background

Disability is a major public health concern worldwide and the situation for children with disabilities is even more serious. The United Nation Convention on the Rights of Persons with Disabilities (UNCRPD) 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”. Some children may be born with a disabling health conditions or impairments, while others may experience disability as a result of illness, injury or poor nutrition. Children with disabilities include those with health conditions such as cerebral palsy, spina bifida, muscular dystrophy, traumatic spinal cord injury, Down syndrome, and children with hearing, visual, physical, communication and intellectual impairments. A number of children have a single impairment while others may experience multiple impairments. For example, a child with cerebral palsy may have mobility, communication, and intellectual impairments. The complex interaction between a health condition or impairment and environmental and personal factors means that each child’s experience of disability is different.⁶

It is estimated that, overall, between 500 and 650 million people worldwide live with a significant impairment. According to the World Health Organization (WHO), around 10 percent of the world’s children and young people, some 200 million, have a sensory, physical, intellectual or mental health impairment. Around 80 percent of them live in low-income countries. Statistics such as these demonstrate that to be born with or acquire an impairment is far from unusual or abnormal. Specialists, however, agree on a working approximation giving a minimum benchmark of 2.5 percent of children aged 0-14 with self-evident moderate to severe levels of sensory, physical and intellectual impairments. An additional 8 per cent can be expected to have learning or behavioral difficulties, or both.⁷

The fifth Rwanda Population and Housing (2022 RPHC) report revealed that 391,775 (3.4%) of the Rwandan population have disabilities. The detailed results on disaggregated data by age group is not yet published⁸. However, the Fourth Rwanda Population and Housing Census (2012 RPHC) reported that approximately 20% (87,900) of the population of persons with disabilities are children between the ages of five and eighteen.⁹ Many disabling conditions in children are preventable. In Africa, one the foremost causes of disability are infectious and communicable disease; the incidence of these diseases have been greatly reduced or eliminated in higher income countries. Other causes include war, trauma, accidents, and congenital and noninfectious diseases. A systematic review conducted by Leonard et al. (2022) reported the risk factors to impairments among children and adolescents which include family factors; biological factors; socioeconomic factors; and environmental factors

⁶ Early Childhood Development and Disability: A discussion paper. Retrieved on https://apps.who.int/iris/bitstream/10665/75355/1/9789241504065_eng.pdf

⁷ Promoting the Rights of Children with Disabilities. Innocenti Digest No. 13, UNICEF

⁸ Fifth Population and Housing Census-2022 (NISR, 2022)

⁹ RWANDA NATIONAL POLICY OF PERSONS WITH DISABILITIES AND FOUR YEARS STRATEGIC PLAN (2021-2024)

such as child neglect and abuse, poor water and sanitation, environmental agents and toxins, accidents, and injuries, etc.

Early identification, referral and management of impairments in children has been emphasized by the National policy of persons with disabilities and its four years' strategic plan (2021-2024) especially the strategic objective related to the strengthening of early identification, diagnostic assessment, and intervention, prioritizing children with disabilities.¹⁰ In response to this, different interventions are being carried out within the health sector. However, lack of evidence on disability determinants and risk factors as well as contributing to the impairments in children constitute a hindrance to the good performance of the above-mentioned interventions.

1.2. Objectives

1.2.1 General objective

The aim of this study is to determine the risk factors and factors contributing to impairments in children and adolescents in Rwanda.

1.2.2 Specific objectives

1. To determine the family factors that may contribute to the impairments among children and adolescents in Rwanda
2. To determine the reported biological factors that may contribute to the impairments among children and adolescents in Rwanda
3. To determine the socioeconomic factors that may contribute to the impairments among children and adolescents in Rwanda
4. To determine the environmental factors that may contribute to the impairments among children and adolescents in Rwanda

1.3 Significance of the study

It is expected that the study results will be used by the MoH/RBC and its partners including UNICEF, NCDA, NCPD, UPHLS and other stakeholders in developing strategies to address the identified problems as well as the interventions to prevent and manage the impairments among children and adolescents with disabilities in Rwanda.

¹⁰https://www.minaloc.gov.rw/fileadmin/user_upload/Minaloc/National_Policy_on_Disability_and_Inclusion_final.pdf

II. Methodology

2.1. Study Design

A mixed method design was used for complementary purposes. In fact, the quantitative method helped to numerically achieve the research objectives. On the other hand, the qualitative method provided the participants with opportunities to tell their stories outside the boundaries of the structured questionnaire, thus bringing depth and clarity to the results. The quantitative approach consisted of using a structured questionnaire for parents/caregivers of children and adolescents with disabilities. The quantitative data collection also consisted of the review of documented factors contributing to impairments in children and adolescents in Rwanda.

The qualitative data collection included focus group discussions (FGDs) with children and adolescents with different disabilities and their parents/caregivers/guardians, as well as in-depth interviews with healthcare providers.

2.2. Data collection tools

2.2.1. Quantitative tools

A quantitative cross-sectional questionnaire and data capture sheet for the reports review were employed.

2.2.2. Qualitative tools

Focus Group Discussions (FGDs) and in-depth interview guides were used.

2.2.3. Tool development

A screening tool developed by Chance for Childhood in collaboration with UNICEF from the study conducted by WHO to detect developmental delays among children aged 0-11 years was adopted to suit this study. The draft questionnaire was presented to the Technical Working Group (TWG) for validation. The TWG is composed by the Ministry of Health, Rwanda Biomedical Centre (RBC) / NCDs Division, the National Council of Persons with Disabilities (NCPD), the National Childhood Development Agency (NCDA), UPHLS, UNICEF, WHO, Humanity and Inclusion (HI), Save the Children and Chance for Childhood. Based on the final version of the questionnaire, a data capture sheet for document review and the qualitative data collection guides were also developed.

2.2.4. Translation

The tools developed in English were translated in Kinyarwanda by an expert translator who is fluent in both English and Kinyarwanda. Forward and backward translation was performed. A consensus meeting was organized between the professional translator, the investigators and UPHLS to have an agreement on the translated version in Kinyarwanda.

2.2.5. Training

A 1-day training of enumerators on the study objectives, data collection tools and process was conducted.

2.3. Study setting

The formative research was conducted in the following districts: Nyagatare and Bugesera in Eastern Province, Huye, Nyanza and Kamonyi in Southern Province, Gasabo in the City of Kigali, Gicumbi and Musanze in Northern Province and Nyamasheke and Rubavu in Western Province. These districts were selected with reference to the Fifth Population and Housing Census, Rwanda, 2022 which showed a high prevalence of Persons with Disabilities in those districts.

2.4. Population and sampling approach

2.4.1. Population

The target group included children and adolescents with disabilities and their parents/caregivers as well as health care providers. We needed to recruit children and adolescents in addition to their parents or caregivers because they were likely to complement the information that was provided by parents or caregivers. Furthermore, parents may not disclose the right information if they contributed to the impairments of their children.

2.4.2. Sample

2.4.2.1. Sample for parents/caregivers of children and adolescents with disabilities

The sample was calculated using the following formula:

$$n = N / (1 + Ne^2)$$

n = sample size

N = estimated number of children and adolescents with disabilities in Rwanda

e = margin of error. The margin of error of 0.05 was considered.

To estimate the total number of children and adolescents with disabilities in Rwanda, we used two references. First, we considered the 2022 census results that revealed that the total number of children aged 0-17 years was 5, 896, 601; 1,499, 628 (25.4%) in urban areas and 4,396,973 (74.6%) in rural areas. Second, we considered the proportion of children and adolescents with disabilities which was reported to be around 11.3% (8). After calculations, we estimated the total number of children and adolescents with disabilities in Rwanda to be 666,316; 169,458 in urban areas and 496,858 in rural areas. Using the formula $n = N / (1 + Ne^2)$, 400 children and adolescents with disabilities were recruited, 102 in urban areas and 298 in rural areas. Considering the total number of persons with disability in the 10 selected study districts as indicated by the 2022 Rwanda Census, the percentages of the 10 districts were found to be: Nyagatare: 13.5%; Gasabo: 11.5%; Bugesera: 11.2%; Nyamasheke: 10.5%; Rubavu: 9.5%; Gicumbi: 9.5%; Huye: 9.0%; Musanze: 8.6%; Kamonyi: 8.4%; and Nyanza: 8.3%. Based

on these percentages, numbers of participants to be recruited from each study district were calculated.⁸

The participants in urban and rural areas were recruited conveniently, considering the different types of disabilities. For the FGDs, 10 participants in each FGD were purposely selected. The selection for both quantitative and qualitative data collection aimed to include parents/caregivers of children and adolescents with different types of disabilities (sensory, physical, mental, and learning/intellectual disabilities).

2.4.2.2 Sample for healthcare providers

At least one participant in each district healthcare setting was purposely selected for qualitative interviews. This was either pediatrician, medical doctor working in pediatric ward and a midwife from maternity ward. Physiotherapist from Rilima and Gatagara specialised orthopedic hospitals, and a genetician from CHUK were also interviewed.

The following were considered:

- Parents to be included in FGDs: Those with CwDs between 0-11 years
- Adolescents to be included in FGDs: 12-17 Years
- For sampling: Balance between males and females, as well types of disability: physical, mental/intellectual, visual, hearing, and speaking disabilities were considered.
- Local sign language interpreter was provided when needed

Table 1: Sample size per categories

Province/City of Kigali	District	Parents/Caregivers of children and adolescents with disabilities			Healthcare providers	Rural/urban
		Quantitative data collection		FGDs	In-depth Interviews	
		Total	Rural	Urban		
Eastern Province	Nyagatare	54	40	14	-Parents -Adolescents	Nyagatare DH Rural & Urban
	Bugesera	45	34	11	Parents	Rilima Rural & Urban
Southern Province	Huye	36	27	9	-Parents -Adolescents	Kabutare DH Urban
	Nyanza	33	25	8	Parents	HVP Gatagara Rural
	Kamonyi	34	25	9	Parents	Remera Rukoma DH Rural
Western Province	Nyamasheke	42	31	11	-Parents -Adolescents	Kibogora DH Rural
	Rubavu	38	28	10	Parents	Gisenyi DH Urban
Northern Province	Gicumbi	38	28	10	-Parents -Adolescents	Byumba DH Rural
	Musanze	34	25	9	Parents	Ruhengeri DH Urban
City of Kigali	Gasabo	46	34	12	-Parents -Adolescents	Kibagabaga DH Rural & urban
Total		400	297	103		

2.5. Data Analysis

Quantitative data were entered in Microsoft excel sheets, then cleaned and imported in SPSS Version 25. Then, the data were analyzed using descriptive statistics including frequencies and percentages for categorical variables as well as means and standard deviations for numerical variables. Cross-tabulations and Pearson Chi-Square (χ^2) test were used to compare results from rural and urban areas, and the level of significance (p-value) was set at 0.05. The qualitative data were analyzed using a thematic approach. Tape-recorded FGDs and interviews were transcribed, and common concepts were coded to generate themes that were then classified into broader categories.

2.6. Ethical considerations

Ethical clearance for this intervention project was obtained from Rwanda National Ethics Committee (Reference Number: 98/RNEC/2023). All participants signed a consent form before data collection. Participation was voluntary with no adverse consequence for non-participation or withdraw from the study.

III. Results

3.1. Results from study participants

3.1.1 Characteristics of children and adolescents included in the quantitative survey

As illustrated in Table 2, participants from rural and urban areas were similar, except for sex and childhood disability type distributions. In fact, most of the participants were males (60.8%) in rural areas and females (53.8%) in urban areas ($p=0.009$). Regarding childhood disabilities, the proportion of visual disability was higher in urban (18.3%) than in rural (7.6%) areas ($p=0.002$). Overall, the mean age of children and adolescents included in the quantitative survey was 8.36 years and children between 0 and 11 years were 74.8% while adolescents were 25.2%. The results also showed that 69.9% of the participants had physical disabilities during childhood, 47.7% had learning or intellectual disability, 42.0% had speaking difficulties, 14.6% had hearing difficulties and 10.4% had seeing difficulties.

Table 2: Characteristics of children and adolescents included in the quantitative survey

Variable	Overall (n=405)	Rural (n=301)	Urban (n=104)	p-value
Mean age	8.36±4.46	8.50±4.37	7.98±4.72	0.289
Age range		0.4-17	0.11-17	
Age Category in Years, n (%)				0.586
0-2	36 (8.9)	23 (7.6)	13 (12.5)	
3-5	90 (22.2)	66 (21.9)	24 (23.1)	
6-11	177 (43.7)	135 (44.9)	42 (40.4)	
12-15	66 (16.3)	51 (16.9)	15 (14.4)	
16-17	36 (8.9)	26 (8.6)	10 (9.6)	
Children vs Adolescents				0.755
Children (0-11)	303 (74.8)	224 (74.4)	79 (76.0)	
Adolescents (12-17)	102 (25.2)	77 (25.6)	25 (24.0)	
Sex				0.009
Male	231 (57.0)	183 (60.8)	48 (46.2)	
Female	174 (43.0)	118 (39.2)	56 (53.8)	
Disability Type				
Physical	283 (69.9)	207 (68.8)	76 (73.1)	0.409
Learning Disability/Intellectually Challenged	193 (47.7)	140 (46.5)	53 (51.0)	0.433
Speaking difficulties	170 (42.0)	121 (40.2)	49 (47.1)	0.218
Hearing difficulties	59 (14.6)	41 (13.6)	18 (17.3)	0.358
Seeing difficulties	42 (10.4)	23 (7.6)	19 (18.3)	0.002
Others	38 (9.4)	32 (10.6)	6 (5.8)	0.143

3.1.2 Family factors that may contribute to the impairments among children and adolescents in Rwanda

Table 3 summarizes the distribution of the study participants by the family factors that may contribute to the impairments among children and adolescents. Most of the respondents (87.2%) were parents

of children or adolescents with disabilities. It was found that only 53.3% of mothers of CwDs lived with their spouses legally, 57.1% in rural areas and only 42.3% in urban areas, and the difference was found to be statistically significant ($p=0.009$). Ten parents of CwDs (2.5%) were reported to have consanguinity.

Table 3: Family factors that may contribute to the impairments among children and adolescents in Rwanda

Variable	Overall	Rural	Urban	p-value
Relationship with the child				0.562
Parent	353 (87.2)	264 (87.7)	89 (85.6)	
Relative	28 (6.9)	22 (7.3)	6 (5.8)	
Caregiver	17 (4.2)	10 (3.3)	7 (6.7)	
Brother/Sister	6 (1.5)	4 (1.3)	2 (1.9)	
Neighbor	1 (0.2)	1 (0.3)	0 (0.0)	
Mother' Marital Status				
Lives with spouse legally	216 (53.3)	172 (57.1)	44 (42.3)	0.009
Lives with an illegal partner	65 (16.0)	47 (15.6)	18 (17.3)	0.685
Separated after delivering CwD	46 (11.4)	31 (10.3)	15 (14.4)	0.253
Lives in conflict	40 (9.9)	29 (9.6)	11 (10.6)	0.781
Single	36 (8.9)	27 (9.0)	9 (8.7)	0.922
Widower	19 (4.7)	13 (4.3)	6 (5.8)	0.547
Separated before delivering CwD	13 (3.2)	7 (2.3)	6 (5.8)	0.086
Dead	2 (0.5)	1 (0.3)	1 (1.0)	0.557
Unknown	11 (2.7)	7 (2.3)	4 (3.8)	0.411
Age of mother at first birth (n=354)				
Mean $\pm$ SD	22.73 $\pm$ 4.349	22.75 $\pm$ 4.31	22.70 $\pm$ 4.48	0.800
Range	15-40	15-40	15-36	
Age of mother at birth of CwD (n=356)				
Mean	29.27 $\pm$ 7.467	29.60 $\pm$ 7.36	28.34 $\pm$ 7.74	0.104
Range	17-50	17-49	17-50	
Age of father at first birth (n=279)				
Mean	27.76 $\pm$ 6.505	27.89 $\pm$ 6.99	27.39 $\pm$ 4.84	0.990
Range	17-64	17-64	19-41	
Age of father at birth of CwD (n=290)				
Mean	34.39 $\pm$ 9.55	35.12 $\pm$ 9.88	32.23 $\pm$ 8.16	0.039
Range	18-75	18-75	19-53	
Any consanguinity between parents of CwD				0.369
No	364 (89.9)	271 (90.0)	93 (89.4)	
Yes	10 (2.5)	9 (3.0)	1 (1.0)	
Don't know	31 (7.7)	21 (7.0)	10 (9.6)	
Not being a parent of the CwD				0.798
No	361 (89.1)	269 (89.4)	92 (88.5)	
Yes	44 (10.9)	32 (10.6)	12 (11.5)	
Are parents of the CwD alive				0.753
Yes, both	356 (87.9)	266 (88.4)	90 (86.5)	
Yes, one	31 (7.7)	23 (7.6)	8 (7.7)	
No one	1 (0.2)	1 (0.3)	0 (0.0)	
Don't know	17 (4.2)	11 (3.7)	6 (5.8)	

The qualitative participants expressed that early pregnancy in adolescents as well as pregnancy over 40 years can cause impairments to children. Many participants also revealed that heredity and genetic factors from parents can contribute to impairments among their descendants. For instance, a health care provider expressed: "Genetic factors from parents can cause impairments, which means that they

can be transferred from parents to offspring”. Another participant said, “some children are born with deformities that are hereditary”.

3.1.3 Biological factors that may contribute to the impairments among children and adolescents in Rwanda

3.1.3.1 Biological pre-natal factors

Overall, the most common identified pregnancy complications as factors that may contribute to the impairments among children and adolescents in Rwanda were maternal under-nourishment (15.8%), malaria during pregnancy (13.8%), bleeding during pregnancy (8.1%) and intra-uterine growth restriction (4.7%). Regarding medications and lifestyle during pregnancy, the most reported factors were maternal alcohol abuse (12.3%), traditional medicine (10.9%), self-administered medications (4.9) and maternal smoking (1.5%) during pregnancy.

Maternal under-nourishment (22.1% vs 13.6%, $p=0.041$), intra-uterine growth restriction (8.7% vs 3.3%, $p=0.027$), and maternal anemia (7.7% vs 2.3%, $p=0.012$) were reported more in urban than in rural areas, and the differences were found to be statistically significant. The results also revealed that 34.3% of the mothers had between only one and three ante-natal visits as indicated in table 4.

Table 4: Biological pre-natal maternal health factors that may contribute to the impairments among children and adolescents in Rwanda

Variable	Overall	Rural	Urban	p-value
Pregnancy complications				
No known issues	231 (57.0)	182 (60.5)	49 (47.1)	0.018
Maternal under-nourishment ^a	64 (15.8)	41 (13.6)	23 (22.1)	0.041
Malaria when pregnant	56 (13.8)	38 (12.6)	18 (17.3)	0.233
Bleeding when pregnant	33 (8.1)	22 (7.3)	11 (10.6)	0.294
Intra-uterine growth restriction	19 (4.7)	10 (3.3)	9 (8.7)	0.027
Other illness/infection ^b	18 (4.4)	13 (4.3)	5 (4.8)	0.835
Maternal anaemia	15 (3.7)	7 (2.3)	8 (7.7)	0.012
Maternal mental illness ^c	9 (2.2)	7 (2.3)	2 (1.9)	0.810
Hypertension	8 (2.0)	4 (1.3)	4 (3.8)	0.112
HIV positive during pregnancy	7 (1.7)	3 (1.0)	4 (3.8)	0.055
Toxemia /Pre-eclampsia/eclampsia (with or without convulsions)	4 (1.0)	3 (1.0)	1 (1.0)	0.975
Maternal asthma	4 (1.0)	2 (0.7)	2 (1.9)	0.263
Gestational diabetes	2 (0.5)	2 (0.7)	0 (0.0)	0.405
Maternal epilepsy	2 (0.5)	2 (0.7)	0 (0.0)	0.405
Meningitis when pregnant	1 (0.2)	0 (0.0)	1 (1.0)	0.089
Do not know	25 (6.2)	17 (5.6)	8 (7.7)	0.455
Medication during pregnancy (excluding iron/folic acid)				
Prescribed by a doctor or health professional	101 (24.9)	75 (24.9)	26 (25.0)	0.987
Self-administered (e.g. from pharmacy)	20 (4.9)	12 (4.0)	8 (7.7)	0.133
Traditional medicine	44 (10.9)	30 (10.0)	14 (13.5)	0.323
Maternal alcohol abuse	50 (12.3)	42 (14.0)	8 (7.7)	0.094
Maternal smoking	6 (1.5)	5 (1.7)	1 (1.0)	0.611
No Medication	236 (58.3)	176 (58.5)	60 (57.7)	0.889
Do not know	16 (4.0)	8 (2.7)	8 (7.7)	0.381
Antenatal care attendance visit				
1 visit	7 (1.7)	6 (2.0)	1 (1.0)	0.187
2 visits	17 (4.2)	12 (4.0)	5 (4.8)	
3 visits	115 (28.4)	75 (24.9)	40 (38.5)	
4 visits	157 (38.8)	121 (40.2)	36 (34.6)	
5 and more visits	78 (19.3)	64 (21.3)	14 (13.5)	
Do not know	26 (6.4)	19 (6.3)	7 (6.7)	
Missed	5 (1.2)	4 (1.3)	1 (1.0)	

^a Vitamin A, iron, folic acid, and iodine deficiency

^b Rubella, CMV, Syphilis, trichomonas, Urinary tract infection during pregnancy) / undiagnosed problem

^c schizophrenia, bipolar and unipolar depression, ant depressive medication

During qualitative data collection, the participants also mentioned several pre-natal factors that they think can lead to impairments. Those factors include maternal anaemia, vaginal bleeding, unprescribed medication, traditional medicines, drug abuse, tobacco use, diseases during pregnancy such as meningitis and cerebral malaria, accident during pregnancy, poor nutrition during pregnancy, ignorance about causes of disability, and not following up with prenatal care during pregnancy. For

instance, a participant declared: “Pregnant mother malnutrition caused by lack of balanced diet can cause impairments to the baby”.

Another participant expressed “mother's failure to check the child's health during pregnancy, use of medicines that are not clinically indicated, not taking medication prescribed during pregnancy, lack of early treatment, skipping pregnancy testing if the mother does not feed well and illness of the mother during pregnancy can all cause impairments in children”. The ignorance as another factor contributing to impairment can be illustrated by the following quote: “low level of knowledge and awareness causes no follow up after a child is discharged from hospital”.

A health care provider also highlighted that there are some idiopathic factors that can lead to impairments among children and adolescents.

3.1.3.2 Biological birth factors

Table 5 illustrates the distribution of the participants according to biological birth factors that may contribute to the impairments among children and adolescents in Rwanda. The top birthplaces were health centres (40.2%) and district hospitals (39.3%). It was reported that 9.4% of children were born at home. It was found that more children from rural areas were born in health centres (44.9% vs 26.9%) and homes (10.0% vs 7.7%) compared to those from urban areas, and the difference was statistically significant ($p=0.010$).

The most reported complications during birth were prolonged labour (36.3%), required resuscitation (24.4%), admission neonatal care unit in hospital (21.2%), caesarean-section (16.3%), neonatal jaundice (6.7%), forceps delivery (5.2%), baby stuck in birth canal (3.7%), breech birth (2.5%). Caesarean-section (24.0% vs 13.6%, $p=0.013$), forceps delivery (9.6% vs 3.7%, $p=0.018$), baby stuck in birth canal (7.7% vs 2.3%, $p=0.012$), cord around the neck (4.8% vs 1.3%, $p=0.038$) and infection (2.9% vs 0%, $p=0.003$) were significantly reported more in urban than in rural areas.

Table 5: Biological birth factors that may contribute to the impairments among children and adolescents in Rwanda

Variable	Overall	Rural	Urban	p-value
Birthplace				0.010
Health Centre	163 (40.2)	135 (44.9)	28 (26.9)	
District Hospital	159 (39.3)	103 (34.2)	56 (53.8)	
Home	38 (9.4)	30 (10.0)	8 (7.7)	
Provincial/Referral Hospital	26 (6.4)	19 (6.3)	7 (6.7)	
Somewhere else (e.g. workplace, during the journey to health facility)	8 (2.0)	7 (2.3)	1 (1.0)	
Health post	6 (1.5)	5 (1.7)	1 (1.0)	
Private Clinic	3 (0.7)	1 (0.3)	2 (1.9)	
Do not know	2 (0.5)	1 (0.3)	1 (1.0)	
Birth attendant				0.647
Trained attendant (e.g. nurse, doctor, midwife)	361 (89.1)	265 (88.0)	96 (92.3)	
Traditional attendant	9 (2.2)	8 (2.7)	1 (1.0)	
Family member / friends	13 (3.2)	11 (3.7)	2 (1.9)	
Other	12 (3.0)	10 (3.3)	2 (1.9)	
No attendant	10 (2.5)	7 (2.3)	3 (2.9)	
Stage of the pregnancy the child was born				0.432
6 th / 7 th month	10 (2.5)	7 (2.3)	3 (2.9)	
8 th month	8 (2.0)	4 (1.3)	4 (3.8)	
9 th month	373 (92.1)	280 (93.0)	93 (89.4)	
9 + months	14 (3.5)	10 (3.3)	4 (3.8)	
Child's birth weight				0.543
< 1kg	4 (1.0)	3 (1.1)	1 (1.0)	
1-1.5 kg	8 (2.0)	5 (1.7)	3 (2.9)	
1.5-2.5kg	31 (7.7)	22 (7.3)	9 (8.7)	
2.5-3.5kg	164 (40.5)	129 (42.9)	35 (33.7)	
> 3.5kg	150 (37.0)	105 (34.9)	45 (43.3)	
Do not know	48 (11.9)	37 (12.3)	11 (10.6)	
Known complications during birth				
Prolonged labor (18 hours+)	147 (36.3)	103 (34.2)	44 (42.3)	0.139
Required resuscitation	99 (24.4)	69 (22.9)	30 (28.8)	0.226
Admitted to neonatal care unit in hospital	86 (21.2)	57 (18.9)	29 (27.9)	0.054
Emergency intervention (caesarian-section)	66 (16.3)	41 (13.6)	25 (24.0)	0.013
Neonatal jaundice	27 (6.7)	18 (6.0)	9 (8.7)	0.346
Forceps delivery	21 (5.2)	11 (3.7)	10 (9.6)	0.018
Baby stuck in birth canal	15 (3.7)	7 (2.3)	8 (7.7)	0.012
Breech birth (not born head first)	10 (2.5)	8 (2.7)	2 (1.9)	0.667
Tight nuchal cord (cord around the neck)	9 (2.2)	4 (1.3)	5 (4.8)	0.038
Infection (baby)	3 (0.7)	0	3 (2.9)	0.003
Other	24 (8.0)	7 (6.7)	31 (7.7)	0.681

In agreement with the quantitative results, delivery at home in the absence of a trained midwife or other professional health care providers, prolonged labor, birth underweight or overweight, post term delivery, forceps delivery and congenital deformities were indicated by qualitative participants as some of the factors contributing to impairments among children. A participant said: “after prolonged

labor spent more than two weeks, at time of delivery you find that the child has a rope around the neck”.

The qualitative results revealed some issues such as poor care of the mother who is on labor from midwives or doctors, mistakes of doctors and nurses, unsafe abortion, unsuccessful surgeries, and birth asphyxia as causes of diseases leading to disability. For example, one participant expressed: “you can stretch a child in a wrong way and cause deformity to her/his limbs due to poor handling.

3.1.3.3 Biological postnatal factors

In general, 29.9% and 26.4% of the children and adolescents with disabilities were reported to have difficulties in feeding and drinking respectively. Regarding the weight for age measurement, the results showed that 12.1% and 5.4% were respectively in yellow and red categories. The most reported health conditions, impairments or difficulties in childhood were cerebral palsy (41.2%) and epilepsy (10.6%). Table 6 illustrates the biological postnatal factors that may contribute to the impairments among children and adolescents as reported by the participants.

Table 6: Biological postnatal factors that may contribute to the impairments among children and adolescents in Rwanda

Variable	Overall	Rural	Urban	p-value
Are the child's vaccinations up to date for their age				0.565
No	10 (2.5)	6 (2.0)	4 (3.8)	
Yes	388 (95.8)	290 (96.3)	98 (94.2)	
Do not know	7 (1.7)	5 (1.7)	2 (1.9)	
Child's nutritional status				
No known issues	221 (54.6)	169 (56.1)	52 (50.0)	0.278
Difficulty in drinking	107 (26.4)	77 (25.6)	30 (28.8)	0.515
Failure to feed	121 (29.9)	84 (27.9)	37 (35.6)	0.141
Failure to thrive (slow / low growth)	124 (30.6)	93 (30.9)	31 (29.8)	0.835
Weight for age during the last measurement				0.093
Green	135 (33.3)	103 (34.2)	32 (30.8)	
Yellow	49 (12.1)	32 (10.6)	17 (16.3)	
Red	22 (5.4)	14 (4.7)	8 (7.7)	
Do not know	42 (10.4)	37 (12.3)	5 (4.8)	
Not Applicable	157 (38.8)	115 (38.2)	42 (40.4)	
Known health condition, impairment or difficulty in childhood				
None	117 (28.9)	95 (31.6)	22 (21.2)	0.044
Cerebral malaria	19 (4.7)	14 (4.7)	5 (4.8)	0.948
Infections (Meningitis, whooping cough, or the measles)	7 (1.7)	5 (1.7)	2 (1.9)	0.860
Hydrocephaly	15 (3.7)	11 (3.7)	4 (3.8)	0.929
Microcephaly	23 (5.7)	15 (5.0)	8 (7.7)	0.303
Epilepsy	43 (10.6)	30 (10.0)	13 (12.5)	0.470
Ear infections (chronic otitis media and ototoxic drugs)	15 (3.7)	8 (2.7)	7 (6.7)	0.058
Sickle cell anemia	7 (1.7)	4 (1.3)	3 (2.9)	0.294
Long-term digestive tract infection (diarrhea)	19 (4.7)	14 (4.7)	5 (4.8)	0.948
Polio	3 (0.7)	2 (0.7)	1 (1.0)	0.761
Cerebral palsy	167 (41.2)	118 (39.2)	49 (47.1)	0.158
Other	95 (23.5)	70 (23.3)	25 (24.0)	0.871
Family History: Any family members with known impairments from birth				
Physical	53 (13.1)	37 (12.3)	16 (15.4)	0.420
Learning Disability/ Intellectually Challenged	34 (8.4)	27 (9.0)	7 (6.7)	0.478
Speaking difficulties	25 (6.2)	17 (5.6)	8 (7.7)	0.455
Hearing difficulties	10 (2.5)	8 (2.7)	2 (1.9)	0.677
Seeing difficulties	8 (2.0)	4 (1.3)	4 (3.8)	0.112
Others	38 (9.4)	32 (10.6)	6 (5.8)	0.143
None	265 (65.4)	200 (66.4)	65 (62.5)	0.466
Do not know	37 (9.1)	27 (9.0)	10 (9.6)	0.844

The individual interviews and FGD participants confirmed the quantitative results as the participants expressed that malnutrition, vitamin deficiencies, high fever for below 5 years, late or lack of vaccination, diseases and seizures can lead to impairments and disability. A participants said: "a child can suffer from a tumor on a certain body part, epilepsy can lead to a child's disability, too much fever

can ruin their brain. When a child is not vaccinated, he/she may have a severe sickness that leads to coma, spending much time on oxygen". Some participants indicated that meningitis causes disabilities among children, infections in the wound can lead to amputation, osteomyelitis and cancer can also lead to deformities among children.

3.1.4 Socioeconomic factors that may contribute to the impairments among children and adolescents in Rwanda

About the child's mother's/female guardian's highest education level, the results indicated lower level of education in rural than urban areas, and the difference was statistically significant ($p=0.007$). In fact, 17.9% and 67.8% in rural areas compared to 14.4% and 54.8% in urban areas had no education and primary education only respectively. Similarly, the level of education for the children's fathers was lower in rural than urban areas ($p<0.0001$): 21.3% of children's fathers in rural areas against only 6.7% in urban areas had no education; 60.8% of children's fathers in rural areas against 47.1% in urban areas had primary education.

The results indicated that the majority (66.6%) of the study participants were in Ubudehe categories 1 and 2. Furthermore, 73.8% of mothers and 51.9% of fathers of the CwDs had no jobs. Table 7 summarizes the socioeconomic factors that may contribute to the impairments among children and adolescents as identified by the study participants.

Table 7: Socioeconomic factors that may contribute to the impairments among children and adolescents in Rwanda

Variable	Overall	Rural	Urban	p-value
Child's mother's/female guardian's highest education level				0.007
No education	69 (17.0)	54 (17.9)	15 (14.4)	
Primary	261 (64.4)	204 (67.8)	57 (54.8)	
Secondary	64 (15.8)	37 (12.3)	27 (26.0)	
Higher education (college, university)	9 (2.2)	5 (1.7)	4 (3.8)	
Not Applicable	2 (0.5)	1 (0.3)	1 (1.0)	
Child's father's/male guardian's highest education level				p<0.0001
No education	71 (17.5)	64 (21.3)	7 (6.7)	
Primary	232 (57.3)	183 (60.8)	49 (47.1)	
Senior	44 (10.9)	24 (8.0)	20 (19.2)	
Higher education (college, university)	10 (2.5)	3 (1.0)	7 (6.7)	
Not Applicable	48 (11.9)	27 (9.0)	21 (20.2)	
Ubudehe category				0.907
Ubudehe category 1	86 (21.2)	64 (21.3)	22 (21.2)	
Ubudehe category 2	184 (45.4)	135 (44.9)	49 (47.1)	
Ubudehe category 3	135 (33.3)	102 (33.9)	33 (31.7)	
Ubudehe category 4	0	0	0	
Child's mother's / female guardian has job				0.525
No	299 (73.8)	225 (74.8)	74 (71.2)	
Yes	99 (24.4)	70 (23.3)	29 (27.9)	
Not Applicable	7 (1.7)	6 (2.0)	1 (1.0)	
Number of workdays per week				0.430
2-3	15 (3.7)	8 (2.7)	7 (6.7)	
4-5	37 (9.1)	28 (9.3)	9 (8.7)	
6-7	4 (1.0)	3 (1.0)	1 (1.0)	
Unpredictable	43 (10.6)	31 (10.3)	12 (11.5)	
Not Applicable	306 (75.6)	231 (76.7)	75 (72.1)	
Child's father's / male guardian has job				0.006
No	210 (51.9)	169 (56.1)	41 (39.4)	
Yes	126 (31.1)	89 (29.6)	37 (35.6)	
Not Applicable	69 (17.0)	43 (14.3)	26 (25.0)	
Number of workdays per week				0.085
2-3	17 (4.2)	10 (3.3)	7 (6.7)	
4-5	43 (10.6)	33 (11.0)	10 (9.6)	
6-7	24 (5.9)	13 (4.3)	11 (10.6)	
Unpredictable	42 (10.4)	33 (11.0)	9 (8.7)	
Not Applicable	279 (68.9)	212 (70.4)	67 (64.4)	

During the qualitative data collection, the participants also highlighted some socio-economic factors that can cause impairments and disability among children such as poverty to seek medical care and

afford assistive devices. A participant said that “poverty to seek medical care during pregnancy, this can cause the mother to give birth to a child who is tired, leading to disability”. Another participant mentioned that poverty during pregnancy leading to the inability to get fruits and balanced food can cause disability. Another participant expressed: “inability to afford necessary equipment like orthosis, sanitary pads, and wheelchairs prescribed at the hospital result in disability”. Belief in evil spirits, tradition drugs and witchcraft were also pointed out as they lead to not seeking medical care from health facilities.

Family conflicts and violence, especially gender-based violence, were also raised. As an example, a participant said: “after delivering a child with disability, the husband abandons the family”. The husband beating his wife regularly can cause physical trauma to unborn baby, declared one of the participants. Poisoning was also raised as an issue as expressed like: “poisoning can also lead to disabilities”.

3.1.5 Environmental factors that may contribute to the impairments among children and adolescents in Rwanda

Table 8 is about the reported environmental factors that may contribute to the impairments among children and adolescents in Rwanda. It was indicated that some parents or guardians rarely or never read or tell stories to their CwDs (41.2%), sing to them (35.3%), do some activities with them (26.7%), teach them how to do different things (21.5%), talk to them (16.0%) or play with them (13.8%). The proportions of CwDs with history of neglect and history of abuse were found to be 32.3% and 11.9% respectively.

The majority (55.6%) of the participants reported using inadequate or polluted water in the family. Regarding the environmental agents, it was reported that 3.5% of the mothers of CwDs were exposed to some toxins or radiation substances during pregnancy. Furthermore, 7.7% of the mothers experienced some problems of reaching health facilities during pregnancy. The results also revealed that 1.2% of the CwDs were exposed to some toxins or radiation substances.

Table 8: Environmental factors that may contribute to the impairments among children and adolescents in Rwanda

Variable	Overall	Rural	Urban	p-value
<i>I play with my child</i>				0.559
Often every day	243 (60.0)	180 (59.8)	63 (60.6)	
A few times a week (at least once a week)	106 (26.2)	82 (27.2)	24 (23.1)	
It's very little or nothing at all	56 (13.8)	39 (13.0)	17 (16.3)	
<i>I talk to my child</i>				0.047
Often every day	244 (60.2)	183 (60.8)	61 (58.7)	
A few times a week (at least once a week)	96 (23.7)	77 (25.6)	19 (18.3)	
It's very little or nothing at all	65 (16.0)	41 (13.6)	24 (23.1)	
<i>I read or tell stories to my child</i>				0.478
Often every day	123 (30.4)	91 (30.2)	32 (30.8)	
A few times a week (at least once a week)	115 (28.4)	90 (29.9)	25 (24.0)	
It's very little or nothing at all	167 (41.2)	120 (39.9)	47 (45.2)	
<i>I sing to my child</i>				0.854
Often every day	139 (34.3)	104 (34.6)	35 (33.7)	
A few times a week (at least once a week)	123 (30.4)	93 (30.9)	30 (28.8)	
It's very little or nothing at all	143 (35.3)	104 (34.6)	39 (37.5)	
<i>I teach my child how to do different things (for the child who has at least one year)</i>				0.285
Often every day	193 (47.7)	146 (48.5)	47 (45.2)	
A few times a week (at least once a week)	125 (30.9)	96 (31.9)	29 (27.9)	
It's very little or nothing at all	87 (21.5)	59 (19.6)	28 (26.9)	
<i>I do some activities with my child</i>				0.088
Often every day	182 (44.9)	144 (47.8)	38 (36.5)	
A few times a week (at least once a week)	115 (28.4)	84 (27.9)	31 (29.8)	
It's very little or nothing at all	108 (26.7)	73 (24.3)	35 (33.7)	
Neglect and Abuse				
The child has/had history of neglect	131 (32.3)	90 (29.9)	41 (39.4)	0.074
The child has/had the history of abuse	48 (11.9)	36 (12.0)	12 (11.5)	0.909
None	271 (66.9)	207 (68.8)	64 (61.5)	0.177
Do not know	3 (0.7)	3 (1.0)	0 (0.0)	0.307
WASH Related Issues				
We use inadequate or polluted water in the family	225 (55.6)	169 (56.1)	56 (53.8)	0.684
There hygiene and sanitation problem in the family	88 (21.7)	64 (21.3)	24 (23.1)	0.699
No problem	166 (41.0)	123 (40.9)	43 (41.3)	0.931
Environmental Agents (eg: toxic waste)				
The mother was exposed to some environmental toxins/radiation substances during pregnancy	14 (3.5)	12 (4.0)	2 (1.9)	0.321
Th child was exposed to some environmental toxins/ radiation substances	5 (1.2)	3 (1.0)	2 (1.9)	0.461
None	344 (84.9)	266 (88.4)	78 (75.0)	0.001
Do not know	49 (12.1)	26 (8.6)	23 (22.1)	<0.0001
Other Environmental Factors				
The mother experienced some problems of reaching to health facilities during pregnancy	31 (7.7)	21 (7.0)	10 (9.6)	0.383
The mother during pregnancy or a child exposed to loud noises	14 (3.5)	9 (3.0)	5 (4.8)	0.382
Injury (ex: Road accidents, Severe head injury) for a child	32 (7.9)	26 (8.6)	6 (5.8)	0.350

A health care provider also highlighted a smaller number of health care providers, shortage of needed materials in health centers like ultrasound and ambulance, and unrevised referral pathway for pregnant women at the delivery stage. Consequently, a health care provider mentioned that late hospital arrival can lead to asphyxia and disability. This can be illustrated by a participant who mentioned: “asphyxia is usually caused by different things such as reaching to hospital late for delivery, and during this process the child may have problems of blood supply to their brain which leads to impairments. In addition to environmental factors, some personal factors contributing to impairments and disability were also raised during qualitative FGDs and individual interviews with healthcare providers. Those factors include drug and tobacco abuse as well as depression. For instance, a participant said: “drug abuse in adolescents can cause impairments”.

3.2. Results from Health Management Information System (HMIS)

The 2022 HMIS report indicated prenatal health conditions which may contribute to impairments. On top there was antepartum haemorrhage (n=5,358), followed by Ectopic pregnancy (n=1,339) and uterine rupture (n=443) as indicated in table 9.

Table 9: Pre-natal health conditions from the 2022 HMIS report which may contribute to impairments

Health condition	Frequency
Antepartum haemorrhage	5,358
Ectopic pregnancy	1,339
Uterine rupture	443
Eclampsia and severe pre-eclampsia	361
Severe malaria in pregnancy	14

Table 10 illustrates the birth health conditions that may contribute to impairments as reported in the HMIS system for the year 2022. The most common reported health conditions which may contribute to impairments were birth weight <2500 gr (n=23,003), prolonged or obstructed labor (n=15,136), premature newborns (n=12,281) and newborns who didn't cry or breath at birth (n=11,017).

Table 10: Birth health conditions from the 2022 HMIS report that may contribute to impairments

Health conditions	Frequency
Birth weight <2500 gr (alive)	23,003
Prolonged or obstructed labor	15,136
Premature newborns (alive) 22-37 weeks)	12,281
Live newborns who didn't cry/breath at birth	11,017
Birth weight ≤2 Kg (alive newborns)	8,622
Women consulted with preterm premature rupture membranes	5,666
Other congenital malformation	1,000
Delivery by vacuum extraction	732

Table 11 illustrates the health conditions that may contribute to the impairments as reported in the HMIS for the year 2022, although the data are generally for the whole population (not specific to children and adolescents). The proportion of acute malnutrition under 5 years was reported to be 0.64%. The most common reported health conditions for the general population which may contribute to impairments include eye diseases (n=917,547), physical trauma other than fractures (n=623,420), road traffic injuries (n=93,815) and ear diseases (n=66,749).

Table 11: Health conditions from the 2022 HMIS report which may contribute to impairments

Health Condition	Frequency
Acute malnutrition under 5 years	10,880 out of 1,708,460 (0.64%)
Eye diseases ^a	917,547
Physical traumas, other than fractures	623,420
Road traffic injuries	93,815
Bone and joint fractures	81
Other injuries	280,398
Ear diseases ^b	66,749
GBV victims with symptoms of physical violence	16,549
GBV victims with symptoms of emotional violence	3,192
Fire/burns	9,667
Severe malaria cases	1,693
Neuro-development disorders	244
Other neurological disorders	1,421

^a Eye diseases including glaucoma, cataract, refractive error, pinguecula, uveitis, presbyopia, diabetic retinopathy, retinopathy of prematurity, allergic conjunctivitis, infectious conjunctivitis, eye trauma, pterygium, trachoma and other eye diseases.

^b Ear diseases including otitis externa, unspecified, disorders of external ear, unspecified, suppurative otitis media, unspecified, acute mastoiditis/acute mastoiditis, chronic mastoiditis, and other ear diseases.

IV. Conclusion, recommendations, and suggested interventions

4.1. Conclusion

To develop strategies and interventions for prevention and management of the impairments among children and adolescents in Rwanda, the study determining the factors that may contribute to those impairments is necessary. The main objective of this study has been achieved with a rigorous methodology and close collaboration with all stakeholders. Family factors, biological, socio-economic, and environmental factors were identified in this study. These include maternal under nourishment (vitamin A, iron, folic acid and iodine deficiency), malaria during pregnancy, maternal alcohol abuse and smoking, use of traditional and non-prescribed medications, early pregnancy in adolescents as well as late pregnancy, difficulty attending health facilities during pregnancy, ignorance and low level of education and poverty, poor interaction between parents among others. Low birth weight <2500 gr, premature newborns (22-37 weeks), and prolonged or obstructed labor were also reported high. Qualitative findings from the parents of Children with Disabilities revealed probable contributing factors such as delivery at home in the absence of trained health care providers, illnesses and bleeding during pregnancy, poor care of the mothers during delivery at health facilities among others. The reported health conditions were dominated by Cerebral Palsy and Epilepsy which resulted from damage to the children's brain. It is, therefore, paramount to consider the identified factors for planning the strategic interventions to reduce the impairments that may lead to disabilities among children and adolescents in Rwanda.

4.2. Recommendations and Suggested Interventions

The following recommendations were suggested as proposed measures to reduce the impairments among children and adolescent in Rwanda. These recommendations are addressed to the parents/guardians, educators, researchers, practitioners, and policy makers.

Recommendation	Suggested Interventions
As part of pregnancy planning, people should consult doctors or midwives to check for any factor that may cause impairments to their children, and take preventive measures accordingly	-Community Health Education Programs: Organize community health education programs that focus on the importance of regular check-ups before and during pregnancy and early childhood. These programs can include informative sessions, workshops, and interactive activities to engage people and raise awareness about the potential factors that may cause impairments to children. Invite doctors and midwives to deliver talks and address common concerns related to prenatal and postnatal care. Provide educational materials, such as brochures and pamphlets, that explain the importance of consulting doctors or midwives for preventive measures. -Peer Support Networks: Establish peer support networks comprising individuals who have firsthand experience with the benefits of consulting doctors or midwives during pregnancy and early childhood. These networks can connect expectant parents, parents, and caregivers with those who have already undergone the process and witnessed positive outcomes. Encourage sharing of personal stories, testimonials, and advice to inspire and motivate others to seek medical consultations. Facilitate regular group meetings, online forums, or social media groups where people can interact, exchange information, and provide emotional support. The peer support networks can also collaborate with healthcare professionals to organize educational events and encourage regular check-ups. -Well trained healthcare practitioners, especially mid wives should be available, accessible, and affordable in all healthcare facilities. -Training of health professionals in all health facilities on prevention of the risk factors and factors contributing to impairments among children and adolescents is also important.
The study revealed that the most common health condition among children was Cerebral Palsy, and prolonged labour has been reported as the highest factor, therefore there should be measures to avoid the prolonged labours at all health facilities	-Training of healthcare providers to be well-equipped with the knowledge of different factors that may contribute to impairments among children and adolescents for better prevention. - Avail well trained healthcare practitioners, especially midwives and medical doctors in all healthcare facilities.

For the benefits of parents and their children, all families having CwDs should be legally married	-Legal Awareness and Advocacy Campaign: Launch a comprehensive legal awareness and advocacy campaign targeting families with CwDs. This campaign should focus on educating families about the importance of obtaining legal marital status and the associated rights and benefits. The campaign can include the following components: -Community engagement: Engage community leaders, religious institutions, and other influential stakeholders to promote the importance of legal marital status and dispel misconceptions or stigmas associated with CwDs. Foster an inclusive environment that supports families in their pursuit of legal recognition.
Unhealthy behaviours such as tobacco, alcohol, or drug abuse especially during pregnancy should be avoided	-Comprehensive Education and Awareness Programs: Implement comprehensive education and awareness programs targeting pregnant individuals and their families to highlight the risks and dangers of tobacco, alcohol, and drug abuse during pregnancy. These programs should provide evidence-based information on the potential harms these substances can cause to the developing fetus and the long-term consequences for the child. -Expert advice and testimonials: Invite healthcare professionals, obstetricians, midwives, and individuals with personal experiences to deliver talks and share testimonies. Hearing from experts and individuals who have successfully overcome substance abuse can have a powerful impact on motivating and educating pregnant women to make healthier choices.
The rate of ante-natal visits to health care facilities should be increased up to 100%.	-Community health workers: Train and deploy community health workers who can act as trusted liaisons between pregnant women and healthcare facilities. These workers can provide information, support, and reminders about the importance of antenatal visits. They can also assist with appointment scheduling, accompanying expectant mothers to healthcare facilities, and addressing any concerns or questions. -Flexible scheduling and extended hours: Work with healthcare facilities to offer flexible scheduling options, including evening or weekend appointments, to accommodate the diverse needs and constraints of

	expectant mothers. This approach can enable women with work or caregiving responsibilities to attend antenatal visits without significant disruption.
Discouraging the attendance to traditional healers or using traditional medicines and foster maternal health services accessibility are urgently needed	-Community workshops and seminars: Organize workshops and seminars led by healthcare professionals who can provide accurate information about the benefits of antenatal care, the role of modern medicine in promoting a healthy pregnancy, and potential risks associated with traditional practices. Address common misconceptions, fears, and cultural beliefs that may influence the preference for traditional healers. -Healthcare infrastructure and affordable healthcare services: Invest in expanding and improving healthcare facilities, particularly in rural or underserved areas, to ensure pregnant women have access to comprehensive antenatal care. Enhance the availability of obstetricians, midwives, and other skilled healthcare professionals who can provide proper medical supervision during pregnancy. -Implement policies and programs that make antenatal care and modern medical services more affordable and accessible, including subsidies, insurance coverage, or sliding-scale fees based on income. Financial incentives can encourage pregnant women to choose evidence-based medical care over traditional healers.
Parents or guardians should be empowered to create conducive environment for their CwDs	-Parenting and child development education is suggested: Offer parenting and child development education programs to pregnant women, providing knowledge and skills to promote the healthy growth and development of their children. Topics can include infant care, nutrition, early childhood stimulation, and positive parenting techniques. -Individualized guidance: Offer individualized guidance and support to parents or guardians to address their specific concerns or challenges in creating a conducive environment for their CwDs. This can be achieved through one-on-one consultations, home visits, or virtual support sessions with professionals specializing in child development or special education. Provide personalized recommendations and resources based on the child's specific needs and abilities.
Every child should be immunized against infectious diseases as per the recommended schedule of immunization.	-Immunization reminders and tracking systems: Implement reminders and tracking systems to help parents and healthcare providers keep track of children's immunization schedules. This can include phone call reminders, SMS notifications, or electronic health records that alert parents and healthcare providers about upcoming vaccinations. Additionally, establish systems to identify and reach out to children who have missed their immunizations to ensure they receive the necessary vaccines.

	-Expanded immunization services: Increase the availability of immunization services by extending clinic hours, establishing satellite immunization centers, or providing mobile immunization clinics. These efforts can help overcome barriers related to distance, transportation, or time constraints, making it easier for parents to bring their children for vaccinations.
As the majority (66.6%) of CwDs' families were in Ubudehe categories 1 and 2, and 73.8% of mothers and 51.9% of fathers of the CwDs had no jobs, interventions for the inclusion of families affected by childhood disability in local development programmes and initiatives is of paramount importance.	-Stakeholder consultations: Engage families, disabled persons' organizations (DPOs), community leaders, government representatives, and other key stakeholders in consultative processes to identify the barriers and gaps in existing local development programs. Incorporate their insights and experiences into the planning and decision-making processes. -Vocational training and entrepreneurship programs: Offer vocational training programs that equip parents or caregivers with practical skills relevant to local job markets. This can include training in areas such as small business management, handicrafts, computer skills, or agricultural practices. Provide support in setting up microenterprises or small businesses, including access to capital, market linkages, and mentorship.
In order to explore all risk factors and factors contributing to impairments among children and adolescent in Rwanda, further studies are needed	-Engage the Universities in conducting longitudinal and experimental to investigate further risk factors and factors contributing factors to the impairments among children and adolescent in Rwanda at PhD level. -Collaborate with the Ministry of Health and other stakeholders to put disability related studies in their research agenda.

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Appendices

Appendix 1: RISK FACTORS AND CONTRIBUTING FACTORS TO IMPAIRMENTS FOR CHILDREN AND ADOLESCENT QUESTIONNAIRE

Child/Adolescent has disability Yes ☐ No ☐		Child's date of birth		Child's gender: F ☐ M ☐	
If no disability, there is no need to ask other questions					
District					
Family information					
1. Parent / guardian Relationship with child:					
2. Age of biological mother at birth of 1 st child : years	3. Age of biological mother at birth of this child: years	4. Age of biological father at birth of 1 st child (if same father):..... years	5. Age of biological father at birth of this child:..... years	7. Are parents blood relatives to each other? Yes ☐ No ☐	8. Is the child adopted? Yes ☐ No ☐
Do not know ☐	Do not know ☐	Do not know ☐	Do not know ☐	Do not know ☐	9. Is the child an orphan? Yes ☐ No ☐
Biological factors					
Pre-natal maternal health					
3. Did you / the mother have any pregnancy complications? (tick and take notes)		TICK	COMMENTS		
	No known issues				
	Intra-uterine growth restriction				
	Maternal under-nourishment (vitamin A, iron ,folic acid and iodine deficiency)				
	Gestational diabetes				
	Toxemia /Pre-eclampsia / eclampsia (with or without convulsions)				
	Hypertension				
	Malaria when pregnant				

	Meningitis when pregnant			
	Bleeding when pregnant			
	HIV positive during pregnancy			
	Other illness / infection(Rubella,CMV,Syphilis, trichomonas, Urinary tract infection during pregnancy) / undiagnosed problem (describe)			
	Maternal anemia			
	Maternal asthma			
	Maternal epilepsy			
	Maternal mental illness (E.g: schizophrenia, bipolar and unipolar depression ,antidepressive medication,)			
	Do not know	☒		
	4. Did you / the mother take any medication during pregnancy? (excluding iron/folic acid) (tick and note)	YES – prescribed by a doctor or health professional	☒	☒
YES – self-administered (e.g. from pharmacy)		☒		
YES – traditional medicine		☒		
Comment				
Maternal alcohol abuse		☒		
Maternal smoking		☒		
Birth history				
5. Where was the child born? (tick)	Health facility	Health post ☒	Health centre ☒ District hospital ☒ Referral hospital ☒	
	Antenatal care attendance/Visit	1 Visit ☒ 4 Visit ☒ 2 Visit ☒ 3 Visit ☒	5 or more visits to any provider	Missed ☒ How many missed:.....
	Home birth			
6. Did you have a birth attendant? (tick)	Trained attendant (e.g. nurse, doctor, midwife) ☒	Traditional attendant ☒	Family / friends ☒ Other ☒ No attendant ☒	

7. At what stage of the pregnancy was the child born? <i>(tick and note exact gestation if known)</i>	6 th / 7 th month 24-29 weeks (Extremely premature)	8 th month 30 -35 weeks (premature)	9 th month 36-40 weeks (term)	9 + months 40 weeks + (overdue)	
8. What was the child's birth weight? <i>(tick and note if exact weight known of estimate)</i>	<1kg = extremely low birth weight 1-1.5kg = very low birth weight 1.5-2.5kg = low birth weight 2.5-3.5kg 3.5kg+ Do not know				
9. Did you / the mother have any known complications during birth? <i>(tick and comment)</i>				TICK	COMMENTS
	No known issues				
	Prolonged labour (18 hours+)				
	Birth asphyxia	required resuscitation			
		oxygen administration			
		Tight nuchal cord (cord around the neck)			
	Breech birth (not born head first)				
	Baby stuck in birth canal				
	Emergency intervention (caesarian-section)				
	Admitted to neonatal care unit in hospital				
	Infection (baby)				
	Neonatal jaundice				
	Forceps Delivery				
Labor induction					
Other					
Health (current)					

Child health (tick and comment)	10. Are the child's vaccinations up to date for their age?	YES	NO	☒	☒
	Check against vaccination schedule				
	11. Child's nutritional status (tick all that apply)	ISSUE	TICK	COMMENT (include age of occurrence)	
		No known issues			
		Failure to feed			
		Failure to thrive (slow / low growth)			
		Weight for age during the last measurement	Red ☒ yellow ☒		
		MUAC during the last measurement	Red ☒ yellow ☒		
	12. Known health condition, impairment or difficulty in childhood? (comment and describe)	HEALTH CONDITION	TICK	COMMENT	
		None			
		Cerebral malaria			
		Infections (Meningitis whooping cough, or the measles)			
		Hydrocephaly			
		Microcephaly			
		Epilepsy			
Ear infections (chronic otitis media and ototoxic drugs)					
Sickle cell anemia					
Long-term digestive tract infection (diarrhea)					
Polio					
Leprosy					
Cerebral palsy					
Other (including undiagnosed condition - describe)					

		TYPE OF DISABILITY	TICK	COMMENT
		None		
		Seeing difficulties		
		Hearing difficulties		
		Speaking difficulties		
		Physical and mobility difficulties		
		Learning Disability/ Intellectually Challenged		
		Other (including undiagnosed)		
		I don't know		
Family history (Immediate blood relatives only – parents, siblings, grandparents, parent siblings- aunts and uncles)	13. Do any family members have any known impairments from birth? (tick all that apply and note person it applies to)	No		
		Visual Impairment (impaired visual acuity, Uncorrected refractive)		
		Hearing impairment		
		Speaking impairment		
		Physical impairment (like walking, use hands,...)		
		Mental impairment		
		Other disability		
		I don't know		
Socioeconomic factors				
Education (circle)	14. What is child's mother's / female guardian's highest education level? No education Primary 1 2 3 4 5 6 Senior 1 2 3 4 5 6 Higher education (college, university)	15. What is the child's father's / male guardian's highest education level? No education Primary 1 2 3 4 5 6 Senior 1 2 3 4 5 6 Higher education (college, university)		

Socioeconomic status (tick and comment if necessary)	16. Ubudehe category Category 1 ☐	Category 2 ☐	Category 3 ☐	Category 4 ☐	
Parent / guardian working patterns	17. Do you / mother / guardian work? How many days per week? (Tick)	0-1		18. Does the father / male guardian work? How many days per week? (Tick)	0-1
		2-3			2-3
		4-5			4-5
		6-7			6-7
		Unpredictable			Unpredictable
					Not applicable
Environmental Factors					
Stimulation	19. As parent or guardian, would you say:	Often every day	A few times a week (at least once a week)	It's very little or nothing at all	
	I play with my child				
	I talk to my child				
	I read or tell stories to my child				
	I sing to my child				
	I teach my child how to do different things (for the child who has at least one year)				
	I do other activities with my child (comment)				
	20. Neglect and abuse	Tick	Comments		
Neglect and abuse	The child has/had history of neglect				
	The child has/had the history of abuse				
WASH related issues	21. Water and Sanitation				
	We use inadequate or polluted water in the family				

	The is a problem with hygiene and sanitation in the family		
	22. Environmental agents		
Environmental agents (eg: toxic waste)	The mother was exposed to some environmental toxins/radiation substances during pregnancy		
	Th child was exposed to some environmental toxins/radiation substances		
Other environmental factors	23. Other Environmental	Tick	Comments
	The mother experienced some problems of reaching to health facilities		
	The mother during pregnancy or a child exposed to loud noises (E.g: Bombing, Continuous loud noise at home, factories)		
	Injury (ex: Road Traffic accidents, Severe head injury, near-drowning) for a child		

Appendix 2: **FOCUS GROUP DISCUSSION GUIDE FOR PARENTS/CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH DISABILITIES**

BROAD QUESTION

According to you, please tell me the causes of disability among children and adolescents.

PROBES

According to you:

- What are the causes of diseases among children and adolescents?
- What are the causes of injuries among children and adolescents?
- What are the causes of deformities among children and adolescents?
- What things in the community contribute to inability to perform usual activities of daily living or social roles among children and adolescents?
- Is there anything from children or adolescents with disability themselves that contributes to their inability to perform usual activities of daily living or social roles?

Appendix 3: **INTERVIEW GUIDE FOR HEALTHCARE PROVIDERS**

BROAD QUESTION

According to your knowledge and experience from your daily practice, what factors do contribute to disability among children and adolescents?

PROBES

According to your knowledge and experience from your daily practice:

- What are common diseases among children in this region
- What are the causes of diseases among children and adolescents?
- What are the causes of injuries among children and adolescents?
- What are the causes of deformities among children and adolescents?
- What things in the society do contribute to inability to perform usual activities of daily living or social roles among children and adolescents?
- Is there anything from children or adolescents with disability themselves that contributes to their inability to perform usual activities of daily living or social roles?

Appendix 4: **DATA CAPTURE SHEET**

District:

Institutions:

Source of information:

N	Items	Number/ specification	Comments
1	Availability of midwives in health canterers		
2	Availability of midwives in District Hospital		
3	Availability and accessibility of prenatal services in Health centers		
4	Availability and accessibility of prenatal services at DH		
5	Availability and accessibility of maternal and post-natal services at Health Centers		
6	Availability and accessibility of maternal and post-natal services at District Hospital		
	Frequent pediatric conditions		
7	Any report with data about factors associated with and contributing to the impairment/health conditions in children and adolescents		
8	Other information		

Appendix 5: **WRITTEN CONFIRMATION THAT CHILDREN BETWEEN 10-18 YEARS ASSENT TO PARTICIPATE IN RESEARCH**

PART ONE: PARTICIPANT INFORMATION SHEET

The purpose of the data collection is to identify factors that may contribute to disability in children and adolescents in Rwanda

Hello,

My name is and I come from a non-governmental organization called UPHLS that works in all regions of the country in research that this organization is doing in collaboration with UNICEF.

UPHLS is therefore conducting research related to identifying some of the causes of disability in children from the womb, birth, during their development and during adolescence and young adulthood. This research will help in finding measures to be taken to fight and prevent the causes of disability in children, nurses and adolescents in Rwanda. This research is being done on parents of children, teenagers and teenagers with all kinds of disabilities in ten regions including yours.

Therefore, when you have been chosen to be a respondent, we ask you to think carefully before agreeing to make an informed decision whether or not to participate in this study. Any decision you make is welcome.

This parenting study will use two different methods. You have been selected to provide information in:

(1) Discussion to complete the questionnaire

If you agree to be one of the informants, we will have an interview that lasts at least between thirty minutes and an hour (30min -1h) depending on the progress. Then the information you provided will be signed with those of other providers, analyzed in a research way and the results will be used to identify the causes of disability so that measures can be taken to combat and prevent them.

(2) Participate in focus group discussions

If you are in a group discussion area, and agree to participate in this study, you will participate in a discussion with eight to ten (8-10) other people. All conversations are recorded but your names will not be revealed. The audio of the conversation will be stored in a secure location. The information recorded in the audio is confidential and will not be heard by anyone but the researchers.

Voluntary participation in this study

Participation in this study is voluntary. You have complete right to accept or refuse. You may also skip a question that you don't want to answer or that is difficult for you. All of that would make no difference to how you were or will be helped. By agreeing to sign this form, you are agreeing to provide information about yourself and to participate in group discussions when your area is selected.

BENEFITS OF THIS RESEARCH

This research will help to identify the causes of disability from infancy, birth, development, or during adolescence and young adulthood, and measures can be taken to fight and prevent disability at an early age.

KEEPING RESEARCH RESULTS CONFIDENTIAL

The findings will be kept strictly confidential. When it is necessary to publish it, no names should appear, even in the presentation of achievements no names should appear.

This is also the case when the results of the research are going to be published internationally.

ABOUT AWARDS

There is no reward given to the informant in this study for his dedication to building Rwanda, especially in helping to prevent disability early.

WHO TO ASK YOU WHEN YOU HAVE A QUESTION

If you have a question about research; you can call Associate Professor **Sagahutu Jean Baptiste** at **0788800152** or write to him at **jeanbaptigol@gmail.com**. You can also call your project representative..... whenever you have a problem. Those two are the representatives of this study.

If you have any questions about your rights, you can call Assistant Professor **Mazarati Jean Baptise**, the representative of the National Committee for the Protection of Researchers at **0788309808** or call its secretary Associate Professor **David Tumusiime** at **0788749398**.

PART TWO: DECLARATION THAT THE INDIVIDUAL ASSENT TO PARTICIPATE IN RESEARCH WITHOUT COERCION

I have been asked to agree to participate in this study, which includes:

(1) *Discussion to complete the questionnaire* ☐

(2) *Participate in focus group discussions* ☐

I have been given the name of the principal investigator whose telephone number I can contact if necessary. I was given the opportunity to ask questions and I was given satisfactory answers. I agree to participate in this study without obligation and I know that I can withdraw at any time without any negative consequences for me or my family.

Names _____
Signature _____
Date _____
(Day/Month/Year)

Witness for accurate reading

A non-literate witness observed that this participant was read information about the study and given an opportunity to ask questions. I confirm that this person assents to participate in the study without coercion.

Name of witness _____
Signature of witness _____
Date _____
(Day/Month/Year)

Data collector

I have carefully read the potential participant in this study or I have seen that he has read the information about this study and that he has been given an opportunity to ask questions. I confirm that he/she assented to participate in the study without coercion.

Names _____
Signature _____
Date _____
(Day/Month/Year)

Appendix 6: PARENTS' CONSENT TO PARTICIPATE IN RESEARCH

PART ONE: PARTICIPANT INFORMATION SHEET

The purpose of the data collection is to identify factors that may contribute to disability in children and adolescents in Rwanda

Hello,

My name is and I come from a non-governmental organization called UPHLS that works in all regions of the country in research that this organization is doing in collaboration with UNICEF.

UPHLS is therefore conducting research related to identifying some of the causes of disability in children from the womb, birth, during their development and during adolescence and young adulthood. This research will help in finding measures to be taken to fight and prevent the causes of disability in children, nurses and adolescents in Rwanda. This research is being done on parents of children, teenagers and teenagers with all kinds of disabilities in ten regions including yours.

Therefore, when you have been chosen to be a respondent, we ask you to think carefully before agreeing to make an informed decision whether or not to participate in this study. Any decision you make is welcome.

This parenting study will use two different methods. You have been selected to provide information in:

(3) Discussion to complete the questionnaire

If you agree to be one of the informants, we will have an interview that lasts at least between thirty minutes and an hour (30min -1h) depending on the progress. Then the information you provided will be signed with those of other providers, analyzed in a research way and the results will be used to identify the causes of disability so that measures can be taken to combat and prevent them.

(4) Participate in focus group discussions

If you are in a group discussion area, and agree to participate in this study, you will participate in a discussion with eight to ten (8-10) other people. All conversations are recorded but your names will not be revealed. The audio of the conversation will be stored in a secure location. The information recorded in the audio is confidential and will not be heard by anyone but the researchers.

Voluntary participation in this study

Participation in this study is voluntary. You have complete right to accept or refuse. You may also skip a question that you don't want to answer or that is difficult for you. All of that would make no difference to how you were or will be helped. By agreeing to sign this form, you are agreeing to provide information about yourself and to participate in group discussions when your area is selected.

BENEFITS OF THIS RESEARCH

This research will help to identify the causes of disability from infancy, birth, development, or during adolescence and young adulthood, and measures can be taken to fight and prevent disability at an early age.

KEEPING RESEARCH RESULTS CONFIDENTIAL

The findings will be kept strictly confidential. When it is necessary to publish it, no names should appear, even in the presentation of achievements no names should appear.

This is also the case when the results of the research are going to be published internationally.

ABOUT AWARDS

There is no reward given to the informant in this study for his dedication to building Rwanda, especially in helping to prevent disability early.

WHO TO ASK YOU WHEN YOU HAVE A QUESTION

If you have a question about research; you can call Associate Professor **Sagahutu Jean Baptiste** at **0788800152** or write to him at **jeanbaptigol@gmail.com**. You can also call the project representative..... whenever you have a problem. Those two are the representatives of this study.

If you have any questions about your rights, you can call Assistant Professor Mazarati Jean Baptise, the representative of the National Committee for the Protection of Researchers and Research Participants at **0788309808** or call its secretary Associate Professor **David Tumusiime** at **0788749398**.

PART TWO: DECLARATION THAT THE INDIVIDUAL CONSENT TO PARTICIPATE IN RESEARCH WITHOUT COERCION

I have been asked to agree to participate in this study, which includes:

(1) Discussion to complete the questionnaire ☐

(3) Participate in focus group discussions ☐

I have been given the name of the principal investigator whose telephone number I can contact if necessary. I was given the opportunity to ask questions and I was given satisfactory answers. I agree to participate in this study without obligation and I know that I can withdraw at any time without any negative consequences for me or my family.

Names _____
Signature _____
Date _____
(Day/Month/Year)

Witness for accurate reading

A non-literate witness observed that this participant was read information about the study and given an opportunity to ask questions. I confirm that this person consents to participate in the study without coercion.

Name of witness _____
Signature of witness _____
Date _____
(Day/Month/Year)

Data collector

I have carefully read the potential participant in this study or I have seen that he has read the information about this study and that he has been given an opportunity to ask questions. I confirm that he/she consented to participate in the study without coercion.

Names _____
Signature _____
Date _____
(Day/Month/Year)

Appendix 7: HEALTH PROFESSIONALS' CONSENT TO PARTICIPATE IN RESEARCH

PART ONE: PARTICIPANT INFORMATION SHEET

The purpose of the data collection is to identify factors that may contribute to disability in children and adolescents in Rwanda

Hello,

My name is and I come from a non-governmental organization called UPHLS that works in all regions of the country in research that this organization is doing in collaboration with UNICEF.

UPHLS is therefore conducting research related to identifying some of the causes of disability in children from the womb, birth, during their development and during adolescence and young adulthood. This research will help in finding measures to be taken to fight and prevent the causes of disability in children, nurses and adolescents in Rwanda. This research is being done on parents of children, teenagers and teenagers with all kinds of disabilities in ten regions including yours.

Therefore, when you have been chosen to be a respondent, we ask you to think carefully before agreeing to make an informed decision whether or not to participate in this study. Any decision you make is welcome.

This parenting study will use two different methods. You have been selected to provide information by participating in individual in-depth interviews. All conversations are recorded but your names will not be revealed. The audio of the conversation will be stored in a secure location. The information recorded in the audio is confidential and will not be heard by anyone but the researchers.

Voluntary participation in this study

Participation in this study is voluntary. You have complete right to accept or refuse. You may also skip a question that you don't want to answer or that is difficult for you. All of that would make no difference to how you were or will be helped. By agreeing to sign this form, you are agreeing to provide information about yourself and to participate in group discussions when your area is selected.

BENEFITS OF THIS RESEARCH

This research will help to identify the causes of disability from infancy, birth, development, or during adolescence and young adulthood, and measures can be taken to fight and prevent disability at an early age.

KEEPING RESEARCH RESULTS CONFIDENTIAL

The findings will be kept strictly confidential. When it is necessary to publish it, no names should appear, even in the presentation of achievements no names should appear. This is also the case when the results of the research are going to be published internationally.

ABOUT AWARDS

There is no reward given to the informant in this study for his dedication to building Rwanda, especially in helping to prevent disability early.

WHO TO ASK YOU WHEN YOU HAVE A QUESTION

If you have a question about research; you can call Associate Professor **Sagahutu Jean Baptiste** at **0788800152** or write to him at **jeanbaptigol@gmail.com**. You can also call your project representative..... whenever you have a problem. Those two are the representatives of this study.

If you have any questions about your rights, you can call Assistant Professor **Mazarati Jean Baptise**, the representative of the National Committee for the Protection of Researchers and Research Participants at **0788309808** or call its secretary Associate Professor **David Tumusiime** at **0788749398**.

PART TWO: DECLARATION THAT THE INDIVIDUAL CONSENT TO PARTICIPATE IN RESEARCH WITHOUT COERCION

I have been asked to agree to participate in this study by taking part in individual in-depth interviews.

I have been given the name of the principal investigator whose telephone number I can contact if necessary. I was given the opportunity to ask questions and I was given satisfactory answers. I agree to participate in this study without obligation and I know that I can withdraw at any time without any negative consequences for me or my family.

Names _____
Signature _____
Date _____
(Day/Month/Year)

Data collector

I have carefully read the potential participant in this study or I have seen that he has read the information about this study and that he has been given an opportunity to ask questions. I confirm that he/she consented to participate in the study without coercion.

Names _____
Signature _____
Date _____
(Day/Month/Year)

Appendix 8: List of Investigators

S/N	Names	Institution	Position	Role
1	Associate Professor Jean Baptiste Sagahutu	UR-CMHS	Postgraduate Coordinator, School of Health Sciences	Principal Investigator
2	Dr Gerard Urimubenshi	UR-CMHS	HoD, Physiotherapy Department	Co-Investigator
3	Dr. Francois UWINKINDI	RBC	NCDs Division Manager	Co-Investigator
4	Dr Emmanuel Manzi	UNICEF		Co-Investigator
5	Francois Xavier KARANGWA	UPHLS	Executive Director	Co-Investigator