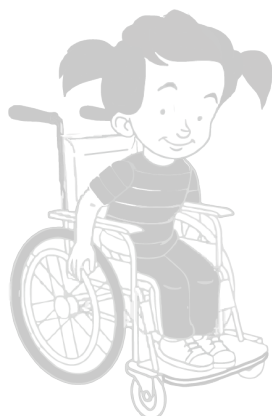


ASSESSMENT OF THE BARRIERS AND CHALLENGES FACED BY MOTHERS AND CHILDREN WITH DISABILITIES TO ACCESS MATERNAL, NEWBORN, CHILD AND COMMUNITY HEALTH SERVICES IN RWANDA

2024



EXECUTIVE SUMMARY

The fifth Rwanda Population and Housing Census (2022 RPHC) report revealed that 391,775 (3.4%) of the Rwandan population have disabilities. RPHC shows that approximately 61,454 of the population of persons with disabilities are children between five and seventeen age group.

Mothers and children with disabilities continue to have limited access to health services including to maternal, child, community and rehabilitation services. The nature of healthcare infrastructure in Rwanda, healthcare provider's perception continues to be challenges in accessing Maternal, Child and Community health and Rehabilitation services, and this continue to affect health and wellbeing of women and children with disabilities.

The Government of Rwanda is committed to achieved universal access to health care by not leaving anyone behind in accessing quality healthcare services including maternal, newborn and child health services. However, the needs and challenges experienced by mothers and children with disabilities while seeking health services at health facilities and in the community are not well documented. Therefore, Umbrella of Organizations of Persons with disabilities in the fight against HIV/AIDS and for health promotion (UPHLS) in collaboration with Rwanda Biomedical Centre (RBC) conducted a study to assess the needs and challenges faced by mothers and children with disabilities in accessing maternal, newborn, child and community health services as well as rehabilitation services.

A mixed method with quantitative and qualitative approaches were conducted from October 2024 to January 2025 in fifteen districts of Rwanda. The primary target population were women and children with disabilities residing in Ruhango, Huye, Nyamagabe, Gisagara, Karongi, Rubavu, Nyabihu, Nyamasheke, Musanze, Gicumbi, Burera, Nyagatate, Bugesera and Gatsibo Districts. A sample of 637 mothers and children with disabilities participated in the study. Key informants' interviews and focus group discussion were conducted among the key district and national stakeholders. Structured questionnaire and interview guide were used during data collection. Structured questionnaire was programmed in Koboo toolbox to allow data collection and data entry at the same time. Ethical approval was secured from Rwanda National Ethics Committee with approval number RNEC/530/2024 all participants signed a consent/assent form prior to the participation in the study. SPSS version 21 was used for data analysis of quantitative data and Nvivo.12 software was used to analysis qualitative data.

A total of 637 participants including 369 children with disabilities and 268 mothers with disability participated in the study. Among 369 parents/caregivers of children with disability participated in the study, of them 268(77.0%) were aged 5 to 10 years, and 202 (54.7%) were male. On other hand, 268 mothers with Disability participated in the study, of them 131(48.9%) were aged 36 years and above, 200(74.7%) had primary education or less, 98(36.6%) were single mothers.

Health facility is geographically inaccessible due to geographical locations with poor roads (11.6%) among mothers with disabilities and mothers of children with disability, the geographical inaccessibility of health facility was 12% among mothers and parents/caregivers of children with physical disability. One third (31.9%) of mothers with disability and parents/caregivers of children with disability had difficulty to access maternal and child health services at Health facility. Mothers and children with mental disabilities are more to experience sexual violence as this was experience by 38.9% of mothers with mental disability and 19.4% of children with mental disability. A total of 436(68.4%) completed continuum of maternal and newborn health care. The quality of Maternal and child health services at health facility was reported as poor by 35.9% of the study participants. Communication was reported by more than 66.7% of mothers with disability experienced as a barrier to communicate with healthcare providers at health facilities. Design of receptions desk, hospital beds, gynecological table, theater room were cited as disability unfriendly and disability exclusive when seeking healthcare services among mothers with disability.

Participation in community health program among mothers with disability was low as only 52.6% reported such participation. Lower participation in community health program was observed among mothers with hearing (28.6%) disability. A total of 143 (53.4%) parents/caregivers of children with disability received reproductive health services from Community health workers and 52.2% received family planning services. Rehabilitation services were not available for mothers and children with disability where 70.2% participants reported that never receive any rehabilitation services.

Mothers and children with disabilities are experiencing health disparities compared to their counterpart. Their access to quality maternal, newborn, child and community health services is poor, likely to have unmet need of rehabilitation services need. There is a need to develop disability-friendly maternal, newborn, child and community health services. Policymaking, health programming, medical equipment/materials and healthcare infrastructures should be disability inclusive. Ministry of health need to develop a special protocol for treating and care of mothers and children with disabilities.

Upgrading infrastructures to improve accessibility including adjustable beds in mother's delivery rooms for inclusivity. Ensure availability of rehabilitation materials such as wheel chair and walking aids, hearing and communication devices, white cane, artificial limbs and surgical appliances ... to the hospital for quick support to everyone with special care

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List of Abbreviation

ANC:	Antenatal care
CBNP:	Community-Based Nutrition Program
CBP:	community-based distribution of family planning services
C-DoTs:	Community Direct Observed Treatment for TB
CHWs:	Community Health Workers
C-MNCH:	Community Mother and New-born Health Program
CwDs:	Children with Disabilities
DMO:	District Mainstreaming Officer
FGDs:	Focus Group Discussion
FP:	Family Planning
GBV:	Gender Based Violence
HIV/AIDS:	Human Immune Deficiency Virus/Acquired Immune deficiency
ICCM:	Integrated Community Case Management
IDIs:	In-Depth-Interviews
KIIs:	Key Informants
MCH:	Maternal Child Health
MoH:	Ministry of Health
NCDA:	National Child Development Agency
NCDs:	Non-Communicable Diseases
NCPD:	National Council of Person with Disabilities
NOUSPR:	National Organization of Users and Survivors of Psychiatry in Rwanda

PNC:	Postnatal Care
PPFP:	Postpartum Family Planning
PWDs:	Persons with Disabilities
RAFA:	Rwanda Amputee Football Amateur
RBC:	Rwanda Biomedical Centre
RMNCH:	Reproductive, Maternal, Newborn and Child Health
RNADW:	Rwanda National Association of Deaf Women
RNEC:	Rwanda National Ethic Committee
RPHC:	Rwanda Population Housing Census
RUB:	Rwanda Union of the Blind
SDGs:	Sustainable Development Goals
SRH:	Sexual Reproductive Health
TB:	Tuberculosis
THT:	Drama club of the Disabled Persons
UNABU:	Rwandan Organization of Women with Disabilities
UNCRPD:	United Nations Convention on the Rights of Person with Disabilities
UPHLs:	Umbrella of Organizations of Persons with Disabilities in the Fight against HIV/AIDS & for Health Promotion
WHO:	World Health Organization
WWDs:	Women with Disabilities

Chapter 1. INTRODUCTION

1.1. Background

Worldwide, an estimated 1.3 billion people or 16% of the global population experience a significant disability. Specifically, 240 million children equivalent to 1 in 10 of children live with one or more disabilities and one in five mothers have disability [1]. The number of persons with disabilities is growing as a result of population increase, ageing, and medical advances that preserve and prolong life. This has increased the demand for health services. Mother and children with disabilities are more susceptible than the general population to secondary health conditions. As a result, mothers and children with disabilities may have greater needs than the general population. Health promotion services for the prevention of further disability and the promotion of health in general are important in determining the quality of life and health status of those with disabilities [2].

The evidence demonstrated that persons with disabilities die earlier, have poorer health, and experience more limitations in everyday functioning than others. Persons with disabilities face barriers in all aspects of the health system. For example, a lack of knowledge, negative attitudes and discriminatory practices among healthcare workers; inaccessible health facilities and information; and lack of information or data collection and analysis on disability, all contribute to health inequities faced by this group [1].

Doing nothing to address these health inequities for persons with disabilities means denying the realization of the universal right to the highest attainable standard of health. Each country has an obligation, under international human rights law and many domestic legal frameworks, to address these inequities. In addition to international law, Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD) lays down that States Parties must recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties must provide persons with disabilities with the same range, quality, standard of free or affordable health care and programs as provided to other persons, including sexual and reproductive health services, population-based health programs and other health services. It also prohibits discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law[3].

Disability inclusion is critical to achieving the Sustainable Development Goals and global health priorities to achieve health for all. Universal health coverage will not be achieved if persons with disabilities do not receive quality health services on an equal basis with others. Investing in universal health coverage for persons with disabilities will benefit not only individuals but also communities [4]. Investing in health equity for persons with disabilities means investing in Health for All, which whilst would likely require additional investments for ensuring equitable access to mothers and children with disability still brings high economic and societal dividends [5].

The fifth Rwanda Population and Housing Census (2022 RPHC) report revealed that 391,775 (3.4%) of the Rwandan population have disabilities. RPHC shows that approximately 61,454 of the population of persons with disabilities are children between the ages of five and seventeen [6]. Mothers and children with disabilities experience significant barriers to accessing health care including maternal, newborn and child health services. Barriers and challenges faced by mothers in accessing MCH services are the following [7, 8]:

- physically inaccessible health facilities;
- lack of appropriate transport to enable them to seek medical care or rehabilitation services;
- lack of communications and accommodation in health care settings;
- untrained healthcare providers and inadequate staffing;
- negative attitudes of health care providers;
- harmful practices, particularly in relation to persons with psychosocial disabilities;
- denial of treatment on grounds of disability.

As with all members of the general population, the health needs of mothers and children with disabilities can vary broadly. The range of maternal, newborn and child health services available to the general population must also be accessible to mothers and children with all types of disability. Care must also be taken to meet the health needs of those with invisible disabilities, particularly those with mental disabilities. Ensuring optimal mental health is an integral part of health service provision, but has received inadequate attention by policy makers and also by society in general. As a result, it imposes an enormous disease burden and an increasing obstacle to development in countries around the world [2].

Specifically, mothers with disability during pregnancy remain at a heightened risk for pregnancy-related health complications[9] . SDG Target 3.1 is to reduce the global maternal mortality ratio to less than 70 per 100 000 live births, however more than half a million mothers with disabilities continue to die as a result of pregnancy related complication. Mothers with disabilities face challenges accessing healthcare and support before, during, and following their pregnancies, which adds to these health disparities. In sub-Saharan countries; the specific needs of women with disabilities may not be addressed in the mainstream pregnancy like providers do not have the needed equipment (like adjustable examination tables, accessible scales) to provide adequate reproductive care, pregnancy, and parenting information for women with disability (books, magazine, health education programs) and inadequately trained healthcare providers among others[10]. The world leaders pledge of leaving no one behind as the underlying principle of the 2030 agenda for sustainable Development goals (SDGs).

Chronic poverty, low education, inadequately trained healthcare professionals, scarcity of resources, substantially affect the quality of life of children and mother's living with disability. Accessibility to healthcare and rehabilitation services for mothers and children with a disability is essential to improving their health and wellbeing[11]. In recognition of this, the United Nations Convention on the Rights of person with disabilities guarantees the fundamental human rights and equitable opportunities to access quality and standard of healthcare. In spite of increased awareness created by UN conventions, mothers and children with disabilities still face numerous challenges to accessing healthcare and rehabilitation services[12].

In the context of reproductive health and rehabilitation services, recent studies revealed that mothers with disabilities are less likely to marry or to have children than the person without disability [13]. A baseline study conducted by Umbrella of Organizations of Persons with Disabilities in the fight against HIV/AIDs and for Health Promotion (UPHLS) in 2019 revealed that fear among person with disabilities to access Sexual Reproductive Health (SRH) services & stigma in family are among the factors contributing to lower Sexual Reproductive Health (SRH) knowledge and service access. Furthermore, Physical challenges especially for wheelchair users and those with limited mobility which make them more vulnerable due to the need of being carried to and from the health centers; Lack of adequate / adapted, maternal newborn and child health facilities, Sexual Reproductive Health (SRH) information, education and communication channels[14]. However, this baseline has not explored barriers and challenges faced by mothers and parents/caregivers of children with disabilities during accessing

Maternal Newborn Child Health, community health services and rehabilitation services.

Umbrella of Organizations of Persons with Disabilities in the fight against HIV/AIDs and for Health Promotion through Every Life Matters project Funded by See You foundation under collaboration with Rwanda Biomedical Center (RBC) conducted the research to explore the Needs and Challenges Faced by Mothers and parents of Children with Disabilities in Accessing maternal and child health facilities including maternal and newborn and child health, family planning, gender-based violence and vaccination and Rehabilitation Services needs of children with disability and mothers with disability as rights holders as declared in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The Government of Rwanda is committed to achieved universal access to health care by not leaving anyone behind in accessing quality healthcare services including maternal, newborn and child health services. However, the barriers and challenges experienced by mothers and children with disabilities while seeking health services at health facilities and in the community are not well documented.

1.2 Aim and objectives

1.2.1. Aims

The purpose of the research is to explore the barriers and challenges faced by mothers and children with disabilities in accessing in maternal, newborn, child, and community health as well as rehabilitation services in Rwanda.

1.2.2. Objectives

The study was guided by the following specific objectives:

1. Identify the barriers and challenges faced by mothers and children with disabilities in accessing health facilities and use of Maternal, Newborn and Child Health services
2. Identify the barriers and challenges faced by mothers and children with disabilities in accessing and use of Community Health Programs
3. Assess the availability, accessibility, affordability and quality of rehabilitation services for mothers and parents/caregivers of children with disabilities.

4. Identify deficiencies in existing policies, programs, and services pertaining to maternal, child, and community health as well as rehabilitation and formulate recommendations for policymakers, healthcare providers and relevant stakeholders to improve access to services and support for mothers and children with disabilities.
5. Generate to develop evidence-based recommendations and propose solutions for addressing identified gaps and challenges.

CHAPTER 2. METHODS

2.1 Study design and Description

A descriptive cross-sectional survey using mixed methods was conducted to gain valuable insights on the needs and challenges faced by mothers and children with disabilities in accessing maternal, newborn, child, and community health as well as rehabilitation services in Rwanda.

Quantitative data involved administering a questionnaire to a diverse group of mothers with disability and parents/caregivers of children with disability to gather information about the level of utilization on Maternal Newborn Child and Community Health (MNCH) services at the facility and in the community. While, qualitative data were collected through focus group discussions (FGDs), in-depth interviews (IDIs), and key informant interviews (KIIs). The participants for qualitative were selected purposively. The FGD participants included community health workers and representative of associations of persons with disability. KIIs were conducted with healthcare providers, Mainstream officers at district level, Director General of Hospitals, Vice Mayors in Charge of social affairs/ Director of Health, National stakeholders from RBC, MOH, NCDA.

2.2 Study site

The study was carried out in 15 districts including 5 districts under Every Life Matters project coverage and additional 10 districts basing on big number of people with disability per district referring to the 5th Population and Housing Census conducted in 2022. The selection criteria were based on geographical situation including rural and urban sectors. The 15 districts are the following: southern province; **Ruhango, Huye, Nyamagabe and Gisagara**; western province; **Karongi, Rubavu, Nyabihu and Nyamasheke**, Northern province; **Musanze, Gicumbi and Burera**; Eastern province **Nyagatare, Bugesera; and Gatsibo**; Kigali city; **Nyarugenge**.

2.3 Study population

The study targeted mothers with disability and parents/caregivers of children with visual, hearing, communication, mental, physical disabilities and multiple disabilities. For parents/caregivers of children with disability, the study focused on parents/caregivers of children with aged 0-10 years while for mothers with disability the study focused on mothers in reproductive age 15-49 years. As there is

no available data on number of mothers with disability in selected districts, a total of 204,269 persons with disabilities in fifteen districts as it included mothers and children with disabilities was considered as primary target population in this research.

In addition to these individuals, healthcare providers at health centers who offer in maternal newborn and Adolescent Sexual Reproductive Health in the selected study areas, leaders of the organization of people with disability, selected stakeholders, and policy makers from relevant government institutions participated in the study.

2.4 Selection of study population

2.4.1 Inclusion criteria

- The study included parents/caregivers of children and mothers with visual, hearing, physical, communication, mental, and multiple disabilities.
- Parents/caregivers of Children with disability (their children must be aged 0 to 10 years)
- Mothers aged 15-49 with disability who have at least one child aged 0 to 10 years
- Provide informed consent or assent if aged below 18 years and their parents consented (Assent completed).
- Living in selected districts, sectors and villages during data collection

2.4.2. Exclusion criteria

- Mothers with disability not consented to participate in the study
- Parent/caregivers not consented their child
- Mothers with disability with serious health conditions that may affect the information given.

2.5 Sampling

Quantitative: To achieve a 5% margin of error with a 95% confidence interval, using a multistage sampling technique with a design effect of 1.5, we determined the sample size using the following formula (Islam Mohammad Rafiqul 2018):

$$n = \frac{DE * Z^2 * p * (1 - p)}{E^2}$$

Where:

n is the minimum sample size

DE is the design effect,

Z is the z-score for the desired confidence level

p is the estimated proportion of the population with the characteristic of interest

E is the desired margin of error

For a 95% confidence interval, the z-score is 1.96. Assuming a conservative estimate of 5% for the population proportion **p**, and using the design effect of 1.5 and margin of error equal to 0.05, the minimum sample size will be the follow:

$$n = \frac{1.5 * 1.96^2 * 0.5 * (1 - 0.5)}{0.05^2} = 576$$

Considering no response rated of 10%, the required sample is 637

Therefore, for 204,269 a population of a minimum sample size was 637.

2.6 Study procedures

District mainstream officer and community health workers listed all mothers with disability and parents/caregivers of children with disability in the selected sectors. a random sampling was applied to select a need number of mothers and children with disability in each sector. Selected participants were invited to participate in the study at cell office. Participants received explanation about the purpose of the study and consenting procedure. The research team ensured that participants have adequately been informed about the study prior to informed consent, considering their disability.

2.7. Sample size

The sample size of population of 204,269 a minimum sample size of 637 was required.

At the district level, convenience sampling was used to select two sectors where mothers and children with disabilities are concentrated, then a simple random sampling technique was used to select respondents from each sector.

In collaboration with UPHLS, the research team worked closely with district official to facilitate data collection procedures. Umbrella of Organizations of Persons with Disabilities in fight against HIV and AIDS and in Health Promotion (UPHLS) worked with local leaders to identify households that have mothers and children with disabilities in selected sectors. Table1 show the sample from each district.

Table 1: Number of study participants per district

		Sample		
Province	District	Mothers of children with disability	Mothers with disability	Total
East	Nyagatare	46	18	64
	Gatsibo	33	21	54
	Bugesera	22	28	50
West	Nyamasheke	38	13	51
	Rubavu	24	26	50
	Karongi	20	16	36
	Nyabihu	28	11	39
North	Burera	30	16	46
	Gicumbi	25	20	45
	Musanze	20	11	31
South	Ruhango	20	26	46
	Huye	25	15	40
	Gisagara	12	21	33
	Nyamagabe	12	17	29
Kigali City	Nyarugenge	14	9	23
Total		369	268	637

Qualitative data

Qualitative data gathered from different key informants from different institutions to know how institutions and policy makers work for barriers and challenges from both caregivers/ parents of children and mothers with disability encounter with in Reproductive Maternal Newborn Child Health (RMNCH) and Rehabilitation services. The sample for qualitative is presented in table 2.

Table 2: Sample for qualitative: Key informants' interview and FGDs

National Level	
Institutions/Organizations	Number of Participants
Rwanda Biomedical Centre, MCCH Division	1
Rwanda Biomedical Centre, NCD Division	1
National Child Development Agency/ NCDA	1
Stroke action Rwanda Drama club of the Disabled Persons (THT) Organization of Women with Disabilities for Health Promotion and Development in Rwanda (OWDHD) Rwanda Union o Little People (RULP) Hope for Single Mothers with Disabilities (HSMD) Rwanda National Union of the Deaf (RNUD) Accociation Generale des Handicapes du Rwanda (AGHR) Rwanda National Association of Deaf Women (RNADW)	8 in Focus Group Discussion
Rwanda Organization of Persons with Deaf Blindness (ROPDB) Organization for the Integration and Promotion of People with Albinism (OIPPA) Rwanda Amputee Football Amateur (RAFA) Rwandan Organization of Women with Disabilities (UNABU) Rwanda Union of the Blind (RUB) National Organization of Users and Survivors of Psychiatry in Rwanda (NOUSPR)	6 in Focus Group Discussion
District level	
Vice mayor social affairs or Director of Heath (one per province)	3
Director of Hospital (one per province)	4
Disability Mainstreaming officer (DMO) in each district	15
Nurse	15
Community Health Workers (CHWs; 15 FGDs)	6

2.8. Data Management

All data including quantitative and qualitative were collected without the presenting name of respondents. Also, for qualitative coding system was used for respondent's privacy. Data was collected in the secure storage and accessible for data manager/ data analysist and principal investigators.

Umbrella of Organizations of Persons with Disabilities in fight against HIV and AIDS and in Health Promotion (UPHLS) is responsible to store raw data and confidentiality of data.

2.8.1 Data collection Procedures

Quantitative data

A structured and semi structured questionnaire was developed and approved by stakeholders. These questionnaires also directed quality of data need to be captured to ensure quality of data. During data collection parents/caregivers of children with disabilities had their own questionnaire for guiding related to information capturing, mothers with disabilities also was directed for their information delivered. We had two languages formatting English and Kinyarwanda. Data collectors was trained to the questionnaires. The questionnaire was programmed in Koboo toolbox to allow data collection and data entry at the same time. The programming ensured the inclusion of data validation and skipping patterns to minimize potential data quality issues. After consenting, the research team ensured that all participants have equal chance to participate in the study despite the type of disability. Expert in communication with persons with disability was hired to facilitate during data collection.

Qualitative data

Focus group discussions (FGDs) applied to complete data gathering with trained data collectors experienced about qualitative data collection then after transcribed and translated was done by experts for further analysis.

Interview guide questionnaire with KIs at National level and district level to establish how policy and program play role to remove barriers and challenges mothers and children with disability encounter with for maternal child health services and Rehabilitation services accessibility, availability and affordability.

Study instrument and tools was developed guided by study objectives. In addition to demographic information that was collected from participants, the following table shows the tools that was developed based on already available instruments with adaptation when needed.

2.9. Data Analysis

Data gathered in these 15 selected districts. SPSS version 21 was used for data analysis to the quantitative data. Findings presented in tables, charts by disaggregated age, sex, and type of disability. After qualitative data collection, all these interviews have been transcribed and translated with emerging

coding for further analysis. Nvivo.12 software was used to analysis qualitative data. To connect both quantitative and qualitative findings, triangulation method was employed.

2.10. Ethical considerations

In accordance with the principles governing research involving human participants, this study ensured that respondents' ethical rights are upheld. Ethical approval was obtained from Rwanda National Ethics Committee with approval number RNEC/530/2024.

2.10.1. Confidentiality

Research team including data collectors had trained to understand the effects from confidentiality, anonymity and other promising to the respondents during research. All respondents were able to complete their consent forms voluntary. These consent forms included all information related to data collection, data storage and usage.

2.10.2. Ethical approval

This Research study was approved by Rwanda National Ethics Committee before conduction. All respondents asked for their informed consent before starting the interviews. Written consent was obtained from each participant, and the participants were told that they had the right not to respond to questions that they do not wish to answer and could voluntarily withdraw from the study when they so wish. Their names and other identifying information would not appear when presenting or publishing the results. Parents/caregiver requested to sign a consent form on their children's behalf, and also children's assent form prior to the participation in the study. Where application participants were given transport facilitation of three thousand Rwandan francs. Provision for the use of an impartial witness in the case of illiterate participants accepted during consenting and data collection procedure.

CHAPTER 3: STUDY FINDINGS

3.1 Demographic characteristics of respondents

Demographic characteristics of study participants are presented in table 3.

Table 3: Socio-Demographics characteristics of respondents

Level	Parents/caregivers of children with disability		Mothers with disability	
	n	%	n	%
Age of a child(years)				
>5	85	23.0	-	-
5-10	284	77.0	-	-
Sex of a child				
Male	202	54.7	-	-
Female	167	45.3	-	-
Child is in school				
Yes	167	52.4	-	-
No	152	47.6	-	-
Age of child caregiver/parents				
15-25	25	6.8	-	-
26-35	142	38.5	-	-
36 and above	202	54.7	-	-
Age of women with disability				
15-25	-	-	44	16.4
26-35	-	-	93	34.7
36 and above	-	-	131	48.9
Education level of parent/caregiver of a child with disability and women with disability				
No Education	86	23.3	82	30.6
Primary Level	218	59.1	118	44.1
Secondary Level and above	65	17.6	68	25.3
Marital of parents/caregivers of children				

with disability and Mothers with disability				
Single mother	40	10.8	98	36.6
Married/living with a partner	249	67.5	102	38.1
Divorced/separated	80	21.7	68	25.4
Family income				
<50,000 RWF	355	96.2	259	96.6
50,000-100,000 RWF	12	3.3	8	3.0
100,000-200,000 RWF	2	0.5	1	0.4
Has health insurance				
Yes	343	93.0	247	92.2
No	26	7.0	21	7.8
Distance to nearest health facility				
Less than 1km	95	25.7	54	20.1
1-5km	136	36.9	78	29.1
More than 5km	110	29.8	98	36.6
Don't know	28	7.6	38	14.2
Religion				
Catholics	109	29.5	91	34.0
Protestants	176	47.7	115	42.9
Adventists	61	16.5	47	17.5
Muslim	10	2.7	8	3.0
No religion	13	3.5	7	2.6
Age of the first delivery				
Less than 18	36	9.8	34	12.8
18-21	146	39.7	89	33.6
22-49	186	50.5	142	53.6

Table 3 present socio-demographic characteristics of children with disability and mothers with disability.

A total of 369 mothers of children with disability participated in the study, 284(77.0%) of their children were aged 5 to 10 years, 202 (54.7%) were male. Of 319 children with disability who supposed to be in school according to their age, only half of them 167(52.4%) children were in school.

The majority 304(82.4%) parents/caregivers of children with disability had only primary education level and less, 249(67.5%) were married/live with a male partner, 355(96.2%) had family income of less than 50,000 RWF per month and 343(93.0%) has health insurance. The distance to the nearest health is 5 km for one third (29.8%) of parents/caregivers of children with disability, 10.6% walk more than 2 hours to reach the nearest health facility. Almost all parents (96.5%) of children with disability are affiliated to religion. The age of the first delivery was between 18-21 years for 39.7% parents/caregivers of children with disability.

On other hand, 268 mothers with disability participated in the study, of them 131(48.9%) were aged 36 years and above, 200(74.7%) had primary education or less, 98(36.6%) were single mothers and the majority (96.6%) of mothers with disability earn less than 50,000 RWF per month. Having health insurance was common among mothers with disability, where 92.2% reported to have health insurance. More than 96% of mothers with disability were affiliated to some religion. A total of 34 (12.8%) gave birth for their first child when they were aged less than 18 years.

3.2 Findings

3.2.1. Specific objective 1: Barriers and challenges faced by mothers and children with disabilities in accessing health facilities and use of Maternal, Newborn and Child Health services

3.2.1.1 Barriers in accessing maternal, Newborn and Child health services at Health Facility

The findings presented in figure 2 shows that 11.6% of mothers with disability and parents/caregivers of children with disability live far from health facility. The barriers to access the health facility due to being located far from the mothers with disability was reported by 14.3% among these with visual disability.

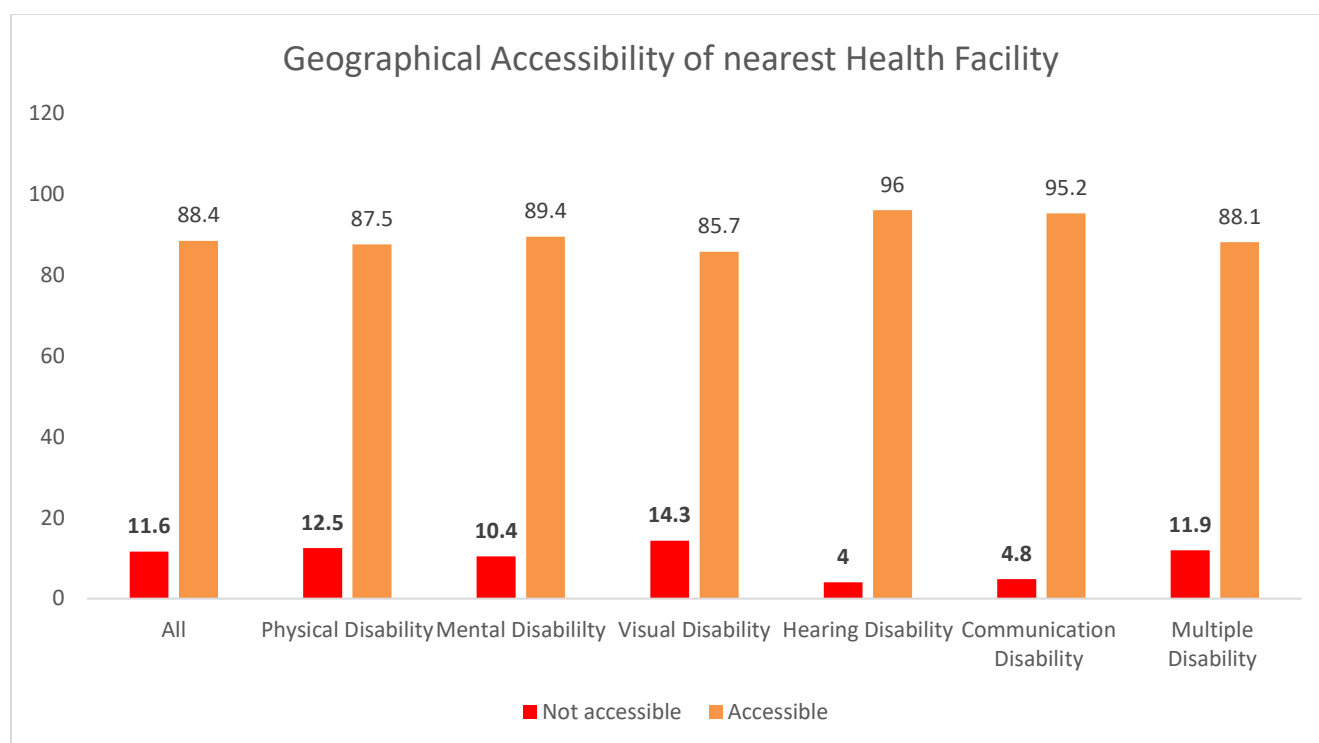


Figure 1: Geographical accessibility of MCH services

More than one third of mothers with disability (36.6%) reside in more than 5 km from the nearest health facility. We estimated geographic accessibility using the Lancet Commission of Global Surgery, defined as the walking distance of within 2 hours to the nearest health facility[15]. Therefore, the results revealed that 11.6% of mothers with disability and parents/caregivers of children with disability walk or assisted to walk for more than 2 hours to reach nearest health facility.

" To reach to health facilities is very difficult for persons with disability due to our geographical location some of health facilities are built to the hills/mountains with very bad roads this limits them to access healthcare services "(KI-Vice mayor in charge of social affair-NYM-001)

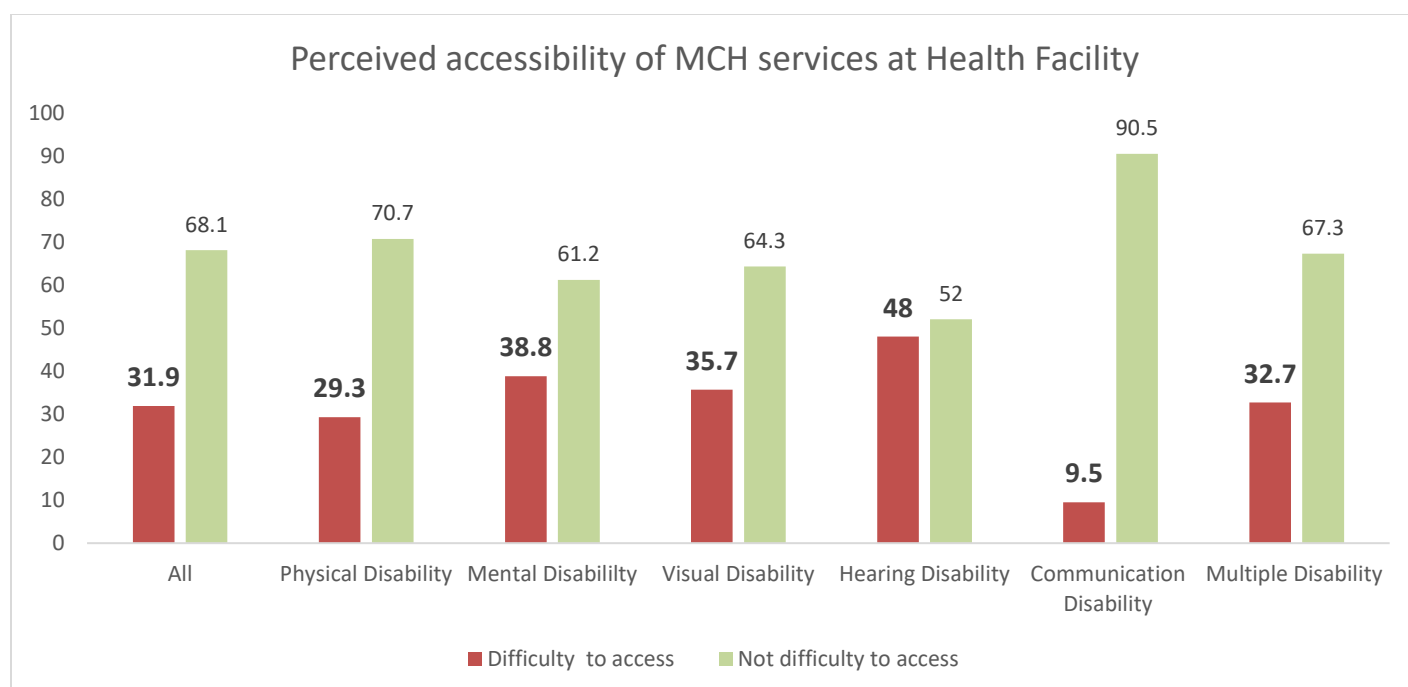


Figure 2: Accessibility of MCH services at Health facility

It was reported that 31.9% of mothers with disability and parents/caregivers of children with disability had difficulty to access maternal and child health services at Health facility. Nearly a half (48%) of mother with hearing disability and mothers of children with hearing disability reported difficult access to MCH services while seeking care.

“To the health facilities there is some pictures on the walls and messages teaches mothers how to breastfeed and taking care of their children so that they could know healthy diet for them..... but it doesn't make sense for me as mothers with visual disability because they can't see them ... it requests any assistant to read them for them what about these who come without their assistant” (KI-UNABU-005)

“Even if, we have stablished measures for caring about people with disabilities we are not yet at 100%. For example, healthcare providers have been trained but they are not able to provide full support to mothers and children with disability due to lack of some specific skills.....” (DG-MH-001)

“Hospital buildings are often built in an old style, so windows are far way, making it difficult for little people to receive Healthcare services at reception and payment ...” (KI-RBC-001)

“The hospital has so many stairs and it is difficult for mothers with disabilities and children with disabilities most of time they come with personal assistant to help them moving from one place to another” (DG-KB-002)

3.2.1.2 Barriers in utilization of maternal, Newborn and child health services at Health facility

The availability of adapted information materials such as braille was a one of the cited barriers at health facilities, as only 19.2 % mothers with disability and parents/caregivers of children with disability found adapted information material when seeking Maternal Child Health (MCH) service at health facility. Communication is barrier in accessing Maternal Child Health (MCH) services where more than 70% of mothers with disability and parents/caregivers of children with disability experienced communication barrier with healthcare providers.

Table 4: Barriers encountered during seeking maternal health services

	Physical	Mental	Visual	Hearing	Communication	Multiple	Total
Barriers	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Adapted information materials available	48(17.1)	14(20.9)	14(33.3)	6(24.0)	5(23.8)	35(17.3)	122(19.2)
Experienced communication barriers	48(28.4)	24(35.8)	15(35.7)	16(64.0)	6(28.6)	60(29.7)	169(26.5)

The lack of training among healthcare workers resulted in challenges in communication between healthcare workers and Mothers with Disability with hearing impairments. The excerpts provided below suggest that the absence of sign language training among healthcare professionals creates a source of frustration amongst Mothers with disability when it comes to accessing maternal and child health services.

“Healthcare providers need to be able to communicate with persons with hearing of communication disabilities because it’s very difficult to communicate with them because it’s very tiring to always arrive and have to communicate using a pen and paper. At each health centre maybe if they can train nurses/midwife in Sign Language that would ease the communication problem”. (Female Nurse – Huye-001).

“Ministry of Health or RBC need to teach healthcare providers sign language, or we (Women with disability) can teach them sign language—maybe the basics that can help them to assist our colleagues when seeking maternal and child health services”. (KI-RNADW-007).

“Health partners implementers need more efforts to teach our healthcare providers sign language, or we can teach them sign language—maybe the basics.....” (KI-Vice mayor in charge of social affair, NYM-001)

“Another challenges that mothers with disabilities face is not receiving timely and quality services because the service providers themselves do not know how to help you and you find that sometimes they make decisions for you. In general, women with disabilities often face obstacles in communicating with healthcare providers, especially for women with hearing and communication disabilities who cannot find someone to help them so that they can get services like other patients at the health facility”. (KI-RAFA-003)

“Most of time mothers with Hearing and speaking disabilities encountered communication barriers because all healthcare providers are not yet trained about sign language.” (DG-S-003)

“Unavailability of medical registers in Braille, directions to some services at health facility are not disability-friendly, at health facility announcements delivered without sign language interpretation, these are some of challenges we are facing to ensure that mothers and children are receiving all MCH package at health facility...” (KI-RBC/MCH-001)

Table 5: Main barriers for mothers with disability in accessing healthcare services

	<i>Physical</i>	<i>Mental</i>	<i>Visual</i>	<i>Hearing</i>	<i>Communication</i>	<i>Multiple</i>	<i>Total</i>
<i>Barriers</i>	<i>n(%)</i>	<i>n(%)</i>	<i>n(%)</i>	<i>n(%)</i>	<i>n(%)</i>	<i>n(%)</i>	<i>n(%)</i>
Transportation	32(20.5)	3(8.3)	8(32.0)	0	1(16.7)	7(22.6)	51(19.0)
Lack of Information	68(43.6)	16(44.4)	12(48.0)	8(57.1)	4(66.7)	15(48.4)	123(45.9)
Distance	16(10.3)	5(13.9)	3(12.0)	0	0	1(3.2)	25(9.3)
Cost	23(14.7)	8(22.2)	1(4.0)	4(28.6)	0	4(12.9)	40(14.9)

This table highlights the main barriers for mothers with disabilities in accessing healthcare services. Within all forms of disabilities lack of information about the available services at health facility was cited by many mothers. Overall, 123(45.9%) of mothers with disability reported the lack of information as main barrier to access the services. Specifically, among mothers with communication disabilities (66.7%) and (57.1%) of those with hearing disabilities reported the lack of information as main challenges to seek Maternal Child Health (MCH) services. Lack of transport facilitation to reach the health facility was reported by 19% of mothers with disability as main barrier to access the service. The lack of transport to reach the health facility was more pronounced among mothers with visual disability (32.0%), and multiple disabilities (22.6%). The cost of health services was reported as a barrier to access Maternal Child Health (MCH) services by 14.9% of mothers with disability.

“Mothers with visual impairments often become pregnancy as result of rape and they often do not have information about Gender based Violence (GBV) services available at the health facilities and other maternal and child health services, as results that the pregnant mother do not attend ANC, delivery at health facility and a child may not be vaccinated”. (KI-RUB-004).

Table 6: Main barriers for Parents/caregivers of children with disability in accessing healthcare services

	Physical	Mental	Visual	Hearing	Communication	Multiple	Total
Barriers	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Transportation	26(21.0)	4(12.9)	1(5.9)	3(27.3)	3(20.0)	28(16.4)	65(17.6)
Lack of Information	40(32.2)	14(45.2)	11(64.7)	6(54.5)	9(60.0)	79(46.2)	159(43.1)
Distance	17(13.7)	3(9.7)	3(17.6)	2(18.2)	2(13.3)	18(10.5)	45(12.2)
Cost	31(25.0)	7(22.6)	2(11.8)	0	1(6.7)	27(15.8)	68(18.4)

This table highlights main barriers faced by parents/caregivers of children with disabilities in accessing child health services where 43.1% reported the lack of child health related information as a barrier. More specifically, parents/caregivers of children with visual disabilities (64.7%) and (60%) of those with communication disabilities reported the lack child health information at high extend compared to others. Lack of information materials reported more with (43.1%) to access child health services also lack of transportation was reported by 17.6% of parents/caregivers of children with disability, 18.4% reported

cost of services as a barrier hinder mothers of children with disabilities to access the Reproductive Maternal Newborn and Child Health services.

“Most Children with disabilities are from poor families always get challenges of healthcare services cost and their families and neighbor seem to be careless to them” (DG – NYM-004)

“We need to acknowledge that some of our hospital buildings, within hospital walking space, and toilets cannot be accessed by wheelchair user, this may affect the services received by women and children with disability...” (DG-S-003)

“For transportation is barrier for persons with disabilities to reach to the health facilities due to our geographical location. Even these persons without disabilities being challenged to reach our roads are very complicated to be used imagine to these wheel chair users, person with visual disabilities,” (Female Nurse-Burera-002)

Despite the observed barriers and challenges in accessing and utilization of MCH services, some of services are used by mothers at good extents. For example, the utilization of ANC services is higher among mothers with disability and mothers of children with disability compared to the general population.

Table 7: Utilization of maternal health services

	Physical	Mental	Visual	Hearing	Communication	Multiple	Total
Variable	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
ANC visit							
Less than 4	60(21.4)	16(23.9)	13(31.0)	8(32.0)	3(14.3)	44(21.8)	144(22.6)
4 and more	220(78.6)	51(76.1)	29(69.0)	17(68.0)	18(85.7)	158(78.2)	493(77.4)
Time for ANC consultation							
>1Hour	280(44.0)	67(10.5)	42(6.6)	25(3.9)	21(3.3)	202(31.7)	637(100.0)
Received regular prenatal services							
Yes	232(82.9)	53(79.1)	28(66.7)	21(84.0)	21(100)	176(87.1)	531(83.4)
No	48(17.1)	14(20.9)	14(33.3)	4(16.0)	0	26(12.9)	106(16.6)
Received regular postnatal services							
Yes	232(82.9)	52(77.6)	31(73.8)	21(84.0)	20(95.2)	171(84.7)	527(82.7)
No	48(17.1)	15(22.4)	11(26.2)	4(16.0)	1(4.8)	31(15.3)	110(17.3)
Mode of Delivery							

Vaginal Birth	210(75.0)	49(73.1)	35(83.3)	21(84.0)	16(76.2)	153(75.7)	484(76.0)
Caesarean section	70(25.0)	18(26.9)	7(16.7)	4(16.0)	5(23.8)	49(24.3)	153(24.0)
Place of delivery							
Health facility	273(97.5)	64(95.5)	38(90.5)	23(92.0)	21(100.0)	197(97.5)	616(96.7)
Home	7(2.5)	3(4.5)	3(7.1)	2(8.0)	-	2(1.0)	17(2.7)
Other	-	-	1(2.4)	-	-	3(1.5)	4(0.6)
Child receive all vaccination	268(95.7)	62(92.5)	37(88.1)	24(96.0)	20(95.2)	195(96.5)	606(95.1)
Had money to cover the cost of services	250(89.3)	58(86.6)	35(83.3)	20(80.0)	20(95.2)	182(99.1)	565 (88.7)

Seventy-seven percent of mothers with disability and those who have children with disability had at least four ANC visits for their recent birth. The attendance of at least ANC visits was less than 70% among mothers and children with visual and hearing disabilities. The latest Rwanda Demographic Health Survey show that 47% of women had at least four ANC visits.

The overall use of prenatal and postnatal care services among mothers with disability and parents/caregivers of children with disability was 83.4% and 82.7% respectively. Compared to respondents with other types of disability, mothers with visual disability and parents/caregivers of children with visual disability were less likely to use prenatal and postnatal care services.

The proportion of cesarean section deliveries is higher 24.0% among mothers with disability and parents/caregivers of children with disability compared to general population (15.0%) as reported by recent DHS. A total of 616 (96.7%) mother delivered at health facility, the proportion of home delivery was 2.7% which is less than what was reported in last DHS (5.4%).

The vaccination coverage among children with disability was high (95.1%) and it is comparable with general population coverage. As more than 90% of study participants has health insurance, it was revealed that 88.7% of study participants were able to pay the cost of received health services.

Table 8: Percent of mothers currently utilizing FP methods and received PPFP before discharge after delivery

Disability	Currently using family planning		Received immediate PPFP method	
	N	%	n	%

Physical	167	59.6	167	59.6
Mental	41	61.2	39	58.2
Visual	24	57.1	23	54.8
Hearing	20	80.0	19	76.0
Communication	13	61.9	13	61.9
Multiple	142	70.3	132	65.3
Total	407	63.9	393	61.7

This table indicate that mothers with disability in accessing Family Planning (FP) and postpartum Family Planning (PPFP). Overall, 63.9% of mothers with disability and parents/caregivers of children with disability were using family planning and 61.7% received PPFP after delivery. The use of FP was slightly low among participants with physical (59.6%) disability and visual (57.1%) disability compare with participants with other types of disability. For PPFP, participants with visual disability had low proportion (54.8%) when compared to others.

Table 9: PNC services mother with disability and parents/caregivers of children with disability

	Physical	Mental	Visual	Hearing	Communication	Multiple	Total
Variable	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Utilization of Postnatal for mothers							
PNC 1	140(89.7)	31(86.1)	21(84.0)	13(92.9)	6(100.0)	28(90.3)	239(89.2)
PNC 2	96(61.5)	27(75.0)	12(48.0)	12(85.7)	6(100.0)	22(71.0)	175(65.3)
PNC 3	93(59.1)	25(69.4)	12(48.0)	12(85.7)	6(100.0)	22(71.0)	170(63.4)
PNC 4	97(62.2)	25(69.4)	13(52.0)	12(85.7)	6(100.0)	22(71.0)	175(65.3)
Utilization of Postnatal services for a baby							
PNC 1	119(96.0)	29(93.5)	16(94.1)	11(100.0)	15(100.0)	161(94.2)	351(95.1)
PNC 2	103(83.1)	22(71.0)	14(82.4)	10(90.9)	15(100.0)	136(79.5)	300(81.3)
PNC 3	101(81.5)	21(67.7)	14(82.4)	10(90.9)	15(100.0)	134(78.4)	295(79.9)
PNC 4	104(83.9)	23(74.2)	15(88.2)	10(90.9)	15(100.0)	136(79.5)	303(82.1)

This table illustrates that mothers with disability and Parents/caregivers of children with disability generally have high utilization of postnatal care (PNC) services. The result show that 89.2% of mother attended PNC1 and 65.3% attended PNC4. Seeking postnatal care service for children with disability as reported by their mother/caregiver, 95.1% attended first PNC and 82.1% attended the fourth PNC.

Table 10: Mothers and children with disability experienced gender-based violence

Disability	Physical	Mental	Visual	Hearing	Communication	Multiple	Total
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Mothers with disability							
Physical	17(10.9)	9(25.0)	5(20.0)	4(28.6)	1(16.7)	2(6.5)	38(14.2)
Sexual	30(19.2)	14(38.9)	8(32.0)	4(28.6)	2(33.3)	10(32.3)	10(25.4)
Economical	11(7.1)	5(13.9)	5(20.0)	1(7.1)	0	3(9.7)	25(9.3)
Emotional	30(19.2)	9(25.0)	8(32.0)	3(21.4)	1(16.7)	10(32.3)	61(22.8)
Children with disability							
Physical	10(8.1)	8(25.8)	0	1(9.1)	1(6.7)	1(9.9)	37(10.0)
Sexual	6(4.8)	6(19.4)	0	1(9.1)	0	8(4.7)	21(5.7)
Economical	6(4.8)	6(19.4)	0	1(9.1)	0	5(2.9)	18(4.9)
Emotional	24(19.4)	6(19.4)	1(5.9)	1(9.1)	4(26.7)	33(19.3)	69(18.7)

Gender Based Violence (GBV) hindering mothers and children with disabilities from accessing Reproductive Maternal Newborn and Child Health (RMNCH) and community Health services. Emotional violence as the most prevalence form of Gender Based Violence (GBV) was reported by 22.8% of mothers with disabilities and 18.7% of children with disabilities. This type of Gender Based Violence (GBV) can lead to mental health challenges and mistrust to healthcare providers. Sexual Based Violence was reported by 25.4% of mothers with disabilities and 5.7% of children with disabilities. Specifically, mothers and children with mental disabilities are more to experience sexual violence as this was experience by 38.9% of mothers with mental disability and 19.4% of children with mental disability.

“Barriers for mothers and children with disabilities feel that they do not have confidence in themselves sometime stigma limits them because they see that they are different from others and they do not even

feel that what they are talking about can be valuable with the people they are going to tell them and they feel that if they talk about their GBV can be molested in the street... ..” (Male Nurse – Gicumbi-001)

“Mothers with physical disability for example little people when had any sexual based Violence it is very hard to disclose such information to someone else even if resulting a pregnancy... .. Most of them they keep quit and keep the pregnancy. In this case it is less likely to seek maternal health services at health facility even at the community due to the fear of harassments” (KI-RULP-002)

Table 11: Mothers and Children with disability experienced GBV and received GBV care

	Physical	Mental	Visual	Hearing	Communication	Multiple	Total
GBV Services	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Mothers with disability							
GBV victims referred to facility by RIB	11(21.6)	8(44.4)	4(30.8)	1(25.0)	2(100.0)	4(30.8)	30(29.7)
GBV victims referred by CHW	10(19.6)	8(44.4)	1(7.7)	2(50.0)	1(50.0)	5(38.5)	27(26.7)
GBV victims HIV+ seroconversion 3 months after exposure	2(6.7)	2(14.3)	0	0	0	1(10.0)	5(7.4)
GBV victims received emergency contraception within 72 hours	1(3.3)	3(21.4)	0	0	0	1(10.0)	5(7.4)
GBV victims received post exposure HIV prophylaxis within 48 hours	1(3.3)	2(14.3)	0	0	0	1(10.0)	4(5.9)
GBV victims referred for care to higher level health facility	6(11.8)	6(33.3)	1(7.7)	1(25.0)	1(50.0)	4(30.8)	19(18.8)
Children with disability							
GBV victims referred	6(18.2)	5(38.5)	0	0	0	4(8.7)	15(15.0)

to facility by RIB							
GBV victims referred by CHW	4(12.1)	3(23.1)	0	0	1(25.0)	4(8.7)	12(12.0)
GBV victims HIV+ seroconversion 3 months after exposure	1(16.7)	1(16.7)	0	0	0	0	2(9.5)
GBV victims received emergency contraception within 72 hours	1(16.7)	1(16.7)	0	0	0	0	2(9.5)
GBV victims received post exposure HIV prophylaxis within 48 hours	2(33.3)	1(16.7)	0	0	0	1(12.5)	4(19.0)
GBV victims referred for care to higher level health facility	4(12.1)	4(30.8)	0	0	0	4(8.7)	12(12.0)

Among mothers with disabilities who experienced any form of violence, only 29.7% of Gender Based Violence (GBV) victims were referred to the healthcare facility by Rwanda Investigation Bureau (RIB), 26.7% were referred by Community Health Workers (CHWs). Only 7.4% of Gender Based Violence (GBV) victims received emergency contraceptive pills within 72 hours and 5.9% received post-exposure HIV prophylaxis within 48 hours. This highlighting referral delays and lack of awareness or resources among service providers to support Gender Based Violence (GBV) victims with disability. These gaps indicate inadequate referral systems, limited access to timely care and insufficient of post Gender Based Violence (GBV) support and this hinder comprehensive access to Reproductive Maternal Newborn Child Health (RMNCH) and community health services for Mothers and children with disabilities.

“for us ... it very hard to live with our partners ... even when there is someone who decided to stay with mother with mental disability community members ignore him Not only our partners but also our children when there are with their colleagues ... they struggle with discrimination due to their mother’s disability. Some of them they tell them that they look like mentally problems.....” (KI-NOUSPR-006)

Table 12: Utilization of the different components of continuum of Care

Service	Frequency (n=637)	%
4 or more ANC contacts	493	77.4
Skilled birth attendance	616	96.7
Maternal PNC	575	90.3
Neonatal PNC	595	93.4
Continuum of care	436	68.4

A total of 436(68.4%) completed continuum of maternal and newborn health care and 31.6% incomplete continuum of maternal and newborn healthcare. Mothers with visual (40.5%) and hearing (40%) disability were more like to have incomplete continuum of maternal and newborn care.

Mothers with disabilities and Parents/caregivers of children with disabilities can have incomplete of continuum of care as results of barriers encounter during their previous attendance such communication barriers, discrimination or services inaccessible.

“For instance: mothers of visual disability are more likely to have communication barriers which can be identified as miscommunication like service providers may tell all patients/clients that “let go there” mothers with visual disabilities cannot know where they mentioned... therefore, there is a need of training for healthcare providers to ensure disability inclusion health services” (KI-RUB-004).

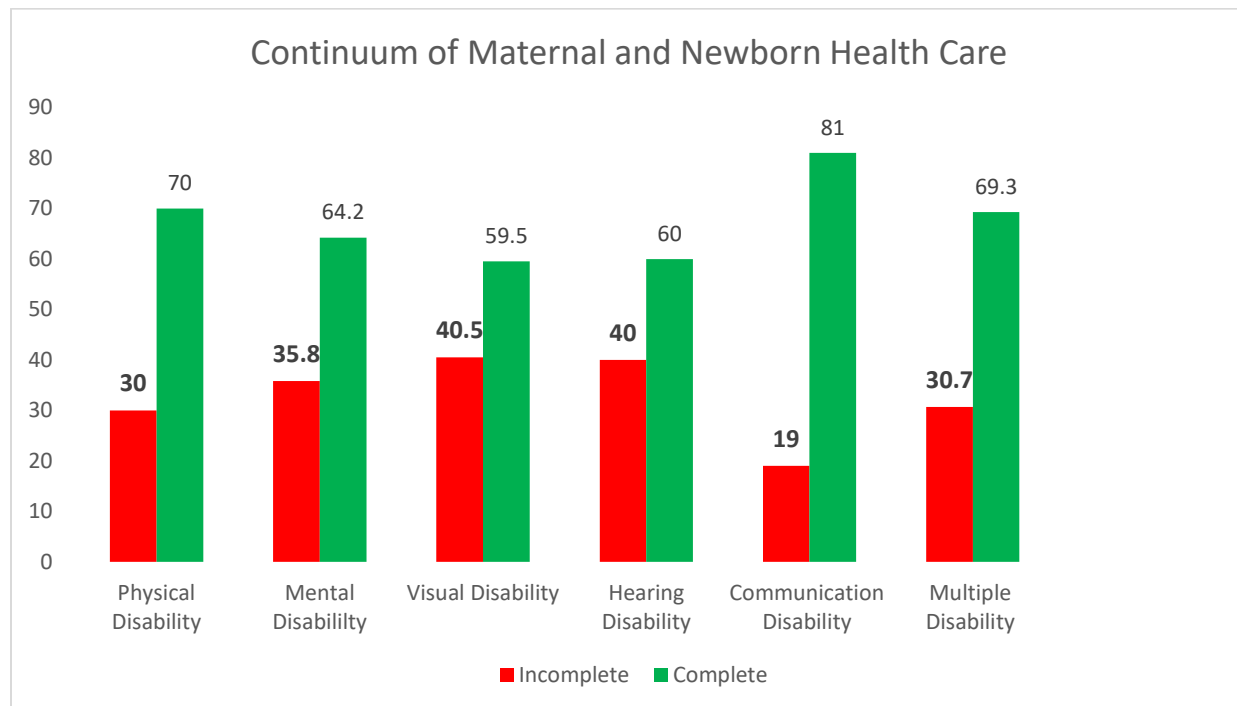


Figure 3: Continuum of Maternal and Newborn care

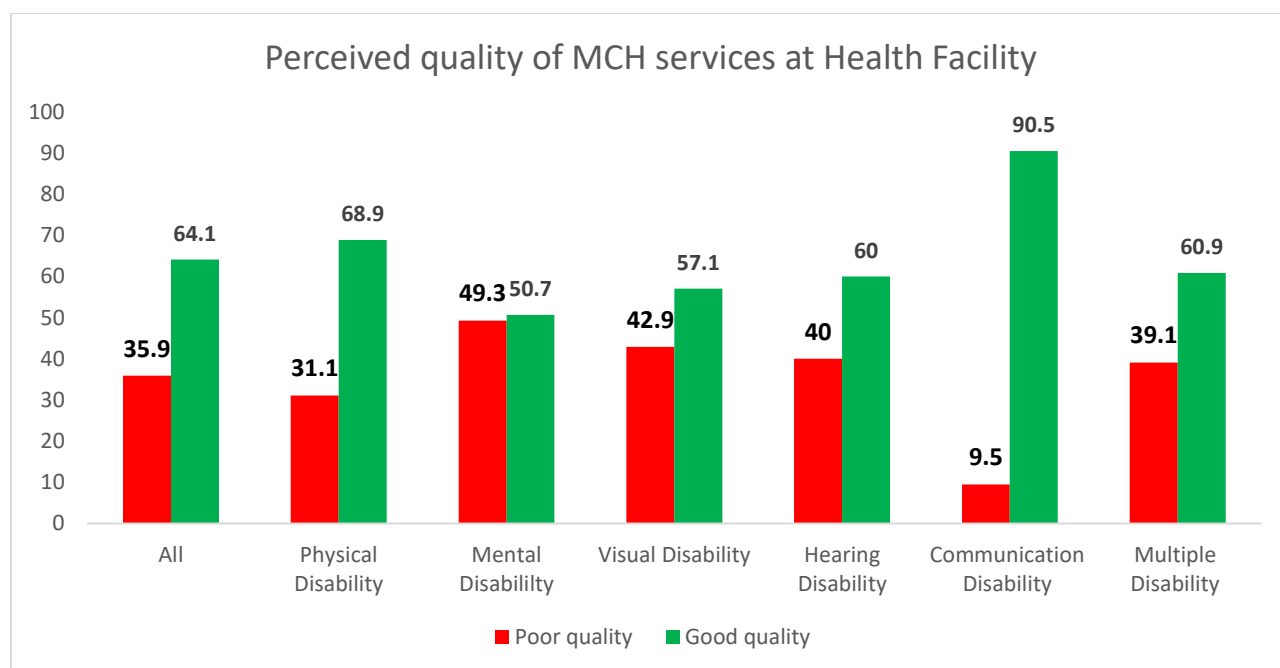


Figure 4: Quality of MCH services at Health Facility

- The quality of Maternal and child health services at health facility was reported as poor by 35.9% of the study participants.
- Nearly a half (49.3%) of mothers with mental disability and mother of children with mental disability rank MCH services as poor.
- Overall, quality of Maternal Child Health (MCH) services at health facility is perceived poor

“For little people is not easy to use that delivery beds even these in maternity room to the health facilities...” (KI-RULP-002)

“Some of Medical tools are inaccessible and the use of beds for women giving birth (ANC rooms) to mothers with disabilities is a serious problem. They have to think on adjustable beds which can be inclusive and easy for everyone to use” (KI-Stroke Action Rwanda-001)

“Our health facilities have shortage of staffs, including nurses and midwives you found that they have big number of patients to care of them this limit everyone to get service with his/her needs especially to persons with disabilities who needs more time to be carefully satisfied due to staff limitation they cannot” (DH-NY-001)

Table 13: Respectful maternity care received by mothers with disability and parents/caregivers of children with disability

	Physical	Mental	Visual	Hearing	Communicatio	Multiple	Total
	n						
Variable	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Receivers of Family’s support period	21(77.5)	48(71.6)	33(78.6)	20(80.0)	18(85.7)	167(82.7)	503 (79.0)
Treated with dignity	259(92.5)	59(88.1)	37(88.1)	23(92.0)	19(90.5)	179(88.6)	576 (90.4)
Providers available	255(91.1))	60(89.6))	37(88.1)	24(96.0)	20(95.2)	174(86.1)	570 (89.5)
Providers are knowledgeable	258(92.1)	61(91.0)	35(83.3)	21(84.0)	21(100.0)	180(89.1)	576(90.4)
Privacy maintained	251(89.6)	59(88.1))	38(90.5)	20(80.0)	19(90.5)	181(89.6)	568(89.2)

Despite the barriers and challenges reported by mothers with disability and parents/caregivers of children with disability, they acknowledged the respectful maternity care while seeking the services. Where 90.5% reported that they have been treated with dignity, 90.4% noticed that healthcare providers had necessary knowledge to give them proper treatment and care, 89.2% revealed that their privacy has been maintained while seeking care at health facility.

3.2.2 Specific objective 2: Barriers and challenges faced by mothers and children with disabilities in accessing and use of Community Health Programs

Rwanda has invested heavily in building a strong health system that is accessible to all citizens using the primary healthcare approach. The Ministry of Health strongly commits to strengthening the capacity of the health sector human resources including community health workers for improved efficiency and effectiveness.

Operating at the village level, Community Health Workers (CHWs) mobilize and educate the community on all health-related matters, collect health data, and currently have been trained to provide low cost-effective curative interventions. The scope of services provided by CHWs currently including Integrated Community Case Management (ICCM), Community Mother and New-born Health Program (C-MNH), Community Direct Observed Treatment for TB and referral (c-DoTS), treatment of malaria in adults and children above five years, community-based distribution of family planning services (CBP), Community-Based Nutrition Program (CBNP) among others.

Mothers and children with disability are more likely to have unmet healthcare needs than their counterpart without disabilities. Due to the structure of our community health program, Mothers and children with disability might be deprived from essential community services due to the lack of information about the available community health program.

3.2.2.1 Use of Community health services among mothers and children with disability

Table 14: Children with disability received treatment for malaria, diarrhea and pneumonia from a Community Health Workers

	Malaria		Pneumonia		Diarrhea	
Disability	N	%	n	%	n	%
Physical	82	29.3	75	26.8	53	18.9
Mental	22	32.8	26	38.8	16	23.9
Visual	13	31.0	13	31.0	7	16.7
Hearing	6	24.0	6	24.0	5	20.0
Communication	4	19.0	3	14.3	3	14.3
Multiple	55	27.2	55	27.2	29	14.4
Total	182	28.6	179	27.9	113	17.7

As reported by their parents, 28.6% of children with disability received treatment of malaria from Community Health Workers (CHWs), 27.9% were treated for pneumonia and 17.7% were treated diarrhea by community health workers. Compared to other disability, Children with mental disability used community health at large extent. The low use of community health services was observed among children with communication disability.

Table 15: Nutritional status of the children with disability as screen by community health workers

	Normal	Moderate malnutrition	Severe malnutrition
Disability	n(%)	n(%)	n(%)
Physical	97(78.2)	19(15.3)	8(6.5)
Mental	25(80.6)	4(12.9)	2(6.5)
Visual	17(100.0)	0	0
Hearing	10(90.9)	1(9.1)	0
Communication	13(86.7)	2(13.3)	0
Multiple	118(69.0)	35(20.5)	18(10.5)

The high rate of children with moderate (20.5%) and severe malnutrition was observed among children with multiple disability (10.5%).

Table 16: Availability and access to the community health program for women with disability

Variable	Physical	Mental	Visual	Hearing	Communication	Multiple	Total
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
CHW was available during the time I need service	131(84.0)	29(80.6)	20(80.0)	11(78.6)	5(83.3)	21(67.7)	217(81.0)
Ever participated in community Health Program e.g Nutrition program	92(59.0)	14(38.9)	20(80.0)	4(28.6)	2(33.3)	9(29.0)	141(52.6)
Sought reproductive health services	93(59.6)	18(50.0)	8(32.0)	4(28.6)	4(66.7)	16(51.6)	143(53.4)
Sought family planning service from Community health worker	84(53.8)	19(52.8)	11(44.0)	6(42.9)	4(66.7)	16(51.6)	140(52.2)

Community health workers were available for 81.0% mothers with disability. Among mothers with disability only 67.7% reported the availability of Community Health Workers (CHWs) when they need the community services. Participation in community health program among mothers with disability was low (52.6%). Lower participation in community health program was observed among mothers with hearing (28.6%), multiple (29.0%), and communication (33.3%) disability. A total of 143 (53.4%)

parents/caregivers of children with disability received reproductive health services from Community health workers and 52.2% received family planning services. Among mothers with hearing disability 28.6% received reproductive health services and 42.9% received family planning services from community health workers.

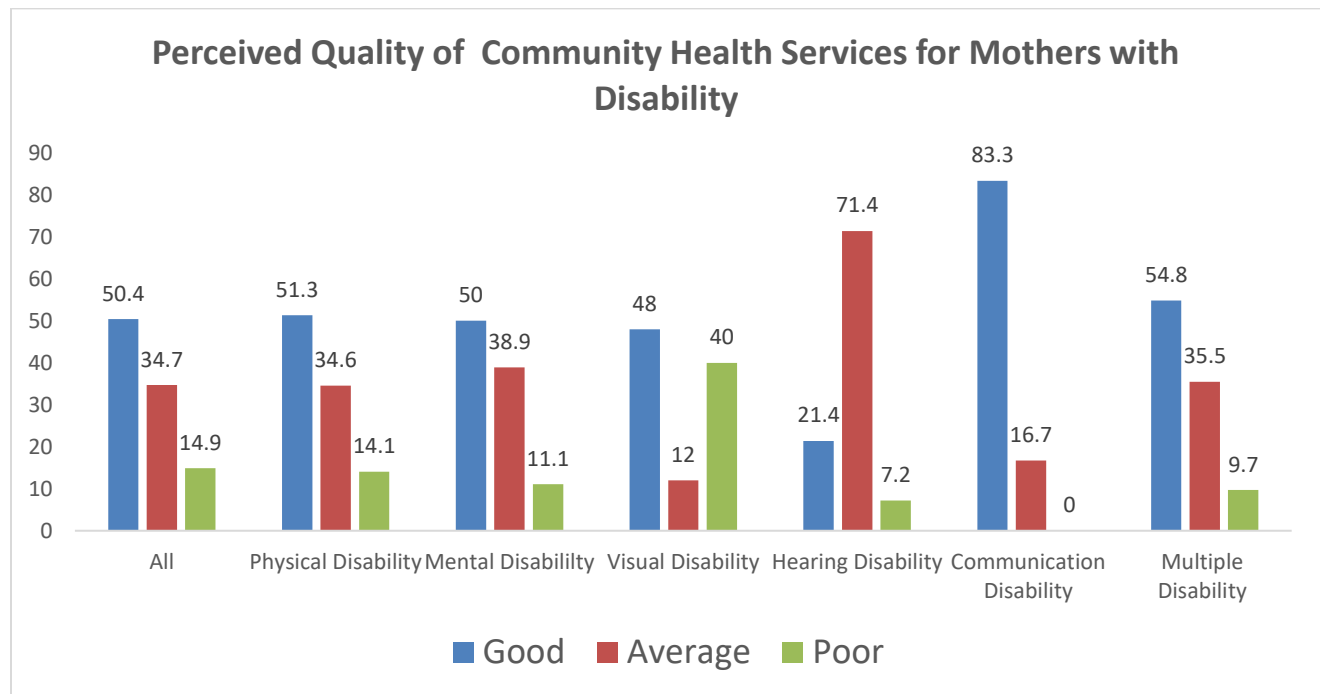


Figure 5: Perceived Quality of Community Health Services for Mothers with Disability

Almost half (50.4%) of mothers with disability perceived good quality of Community Health Workers (CHW) services where 14.9% reported to have received poor quality of community health services. Among mothers with visual disability 40% perceived poor quality of community health services.

“We are aware that mothers with hearing disability had concerns of information being provided in inaccessible formats at health facility, for example at the antenatal class, they had pictures and used actions to explain to us how we breastfeed our kids. I could not see anything. It did not make sense for me to attend further”. (KI- UNABU-005).

3.2.2.2 Challenges faced mothers with disability and parents/caregivers of children with disability

The findings presented in figure 5 revealed that 66.7% of mothers with communication disability, 85.7% of mothers with hearing disability, 80.6% of mothers with multiple disability, and 64% of mother with visual disability reported to experienced communication barrier when seeking community health services.

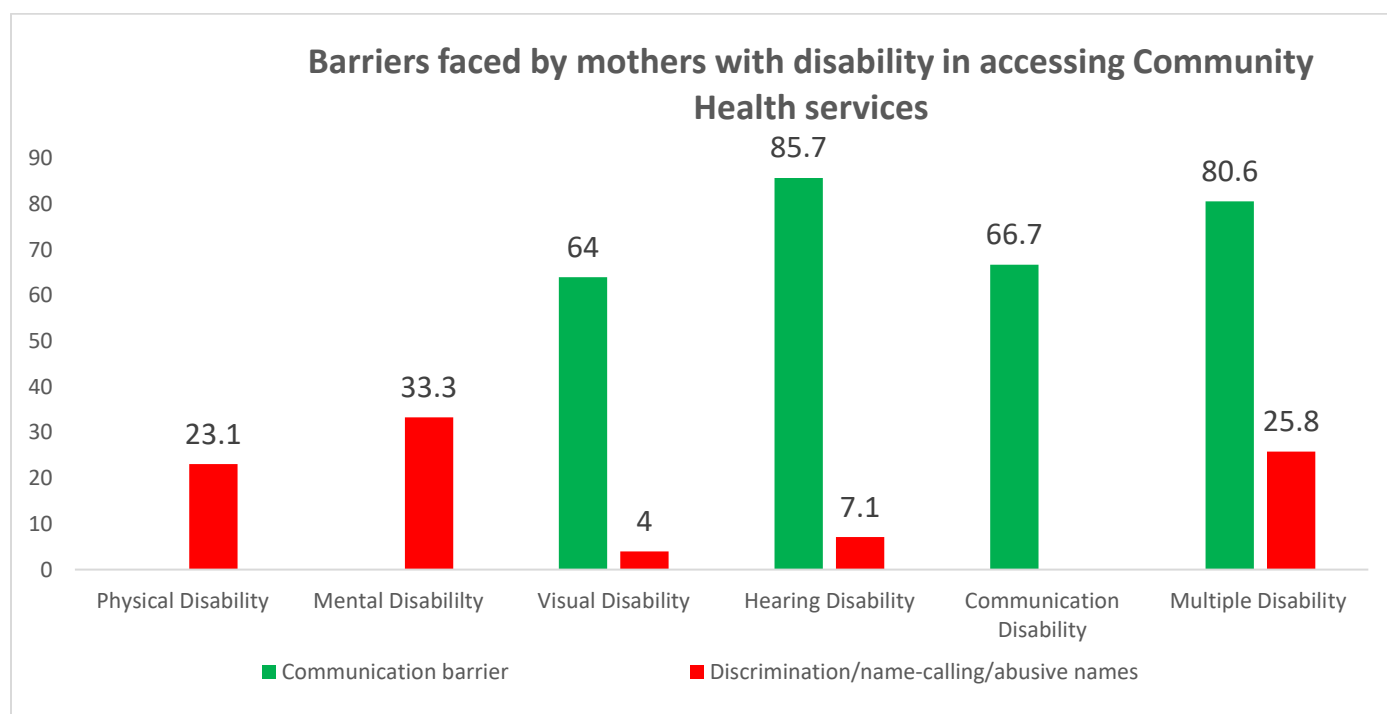


Figure 6: Barriers faced by mothers with disability in accessing community health services

Discrimination, name-calling and abusive names were cited as barrier to access community health services as reported by 33.3% of mothers with mental disability. 25.8% of mothers with multiple disability experienced discrimination while seeking community health services.

Another cited barrier to access community health services was the knowledge and competence of community health workers. The Community Health Workers (CHW) explained that they do not have required training to understand the needs of women and children with disability. Community Health Worker (CHW) said that “we have limited understanding of the needs of mothers and children with disabilities, as we did not receive enough training on how we can assist them”. (FGDs-Male CHW-001)

“Mothers with disabilities and mothers of children with disabilities especially those with mental disabilities we meet with different challenges to access health services to the health facilities because people with mental disabilities are more likely to be discriminated due to our personal characters. It surprises the healthcare providers that we get pregnant. It’s like we do not have functional reproductive systems. They need to be educated that we too have functional reproductive systems, and it is normal for us to be pregnant as we are women too”. (KI-NOUSPR-006)

Table 17: Availability and access to the community health program for parents/caregivers of children with disability

Services	Physical	Mental	Visual	Hearing	Communication	Multiple	Total
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
CHW was available during the time I need service	114(91.9)	24(77.4)	16(94.1)	10(90.9)	15(100.0)	148(86.5)	327(88.6)
Ever participated in community Health Program	78(62.9)	19(61.3)	9(52.9)	6(54.5)	8(53.3)	104(60.8)	224(60.7)
Attended monthly nutritional program	39(31.5)	7(22.6)	4(23.5)	3(27.3)	5(33.3)	47(27.5)	105(28.5)

Community health workers were available when needed as reported by 88.6% mothers of children with disability. Participation in community health program e.g election of Community Health Workers (CHWs) was low as only 60.7% of parents/caregivers of children with disability participated in such activities. This participation was lower among parents/caregivers of children with communication disability (53.3%).

This highlight that parents/caregivers of children with disabilities are not informed about available community health services. Inaccessibility of services, poor quality of service, communication barriers and discrimination lead to poor participation in community health services.

" We need more training about caring person with disabilities even these with visual disabilities they have their special walking styles with their assistant but we do not know...." (FGD-Male CHW- 003)

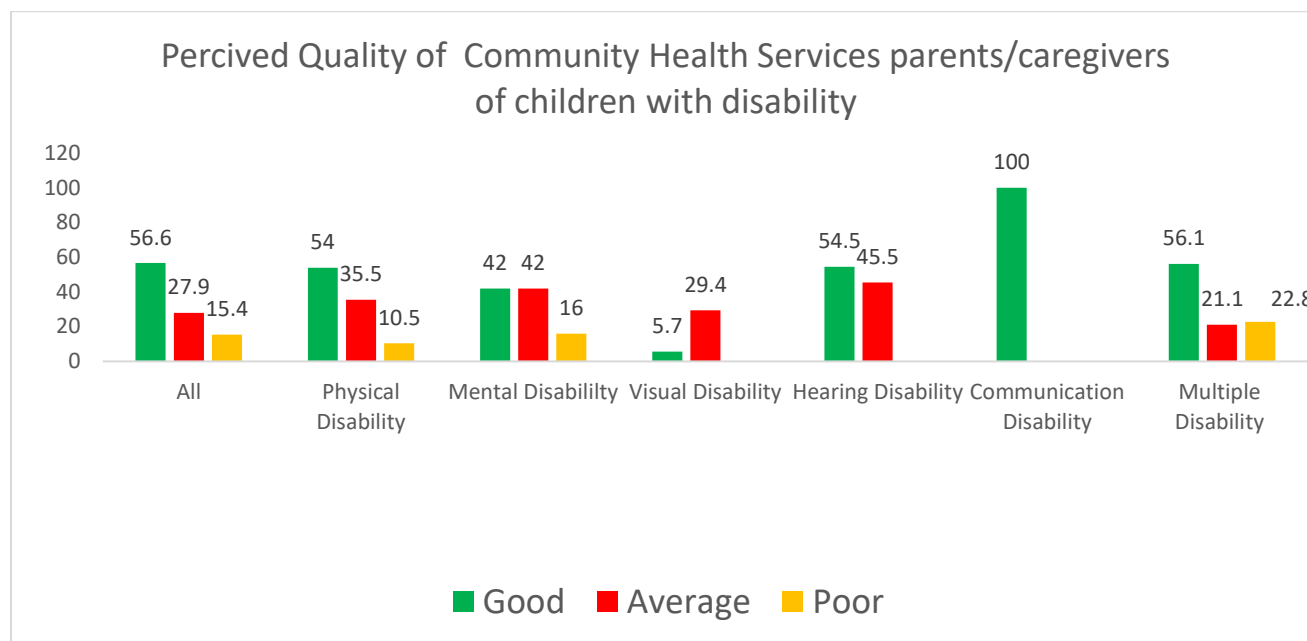


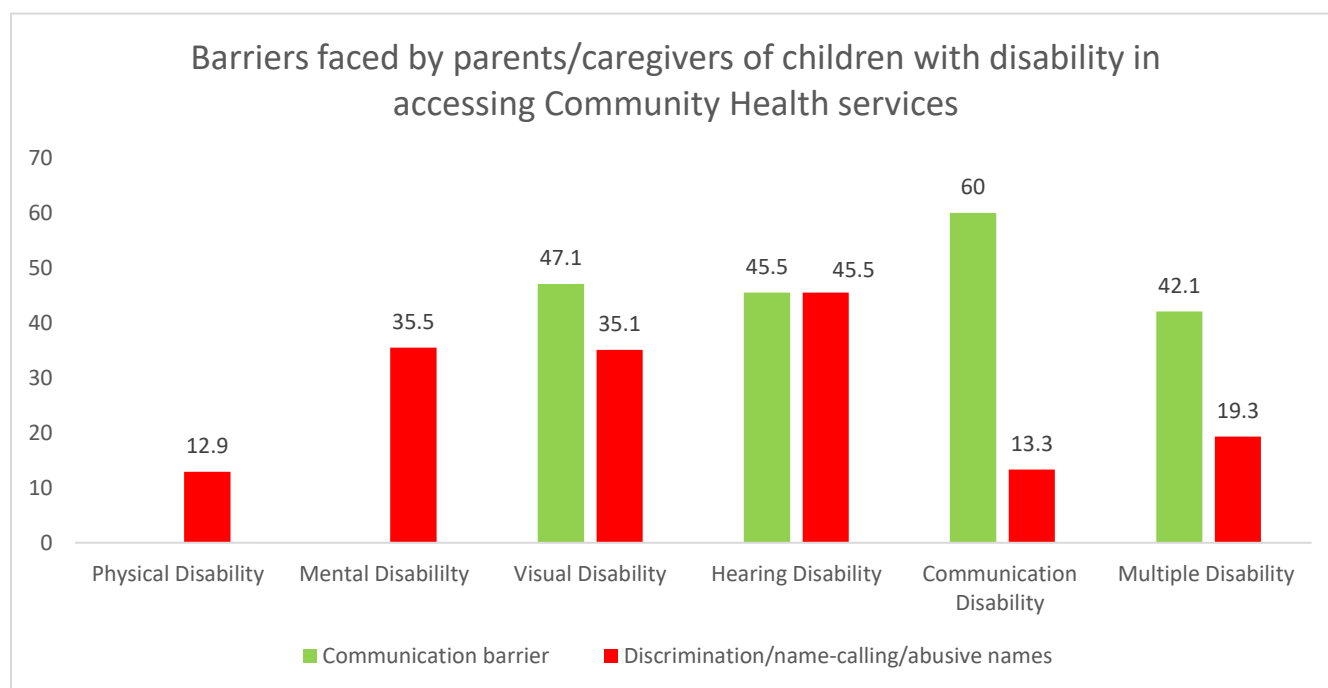
Figure 7: Perceived quality of Community Health Services

Poor quality of community health services was reported by 22.8% mothers of children with multiple disability and 16% of mothers of children with mental disability.

“Community Health Workers (CHWs), they do not apply special care for mothers with disabilities, sometime mothers have challenges to meet with them where services will be delivered and you found that Community Health Workers (CHWs) do not even want to have special discussion with you and sometimes want to discriminate you because they want to receive you as other people without Disabilities” (KI-UNABU-005)

“Community Health Workers (CHWs) provides services to persons with disabilities but they are not well trained at all. For Example; community Health workers (CHWs) they take a person with epilepsy as Persons with Disabilities you found that they are not being able to differentiate diseases and disability.....” (KI-THT-006)

“During monthly growth monitoring for children under five, we are missing the specific number of children with disability who demonstrated poor nutrition status, this affect disability specific Nutritional interventions”(Female Nurse- Karongi-002)



Discrimination as barrier to access community health services was reported by 45.5% of mothers of children with hearing disability, 35.5% of parents/caregivers of children with mental disability and 35.1% of parents/caregivers of children with visual disability. Communication barrier when seeking community health services was reported by 60% of parents/caregivers of children with communication disability and 47.1% of parents/caregivers of children with visual disability.

“Persons with disabilities are mostly being hidden in their families. The one who is able to give birth in the family is treated as a criminal which means that a persons with disabilities is seen as having no right to give birth.” (KI-RUB-004)

"Parents hide their children with disabilities and refuse to reach out to others. For example: when parents come to vaccination some of them with children with disabilities refuse to attend due to affecting other parents roughing them...." (FGD-Female CHW-005)

“When we reach someone who is hearing and communication disability.... find that we are unable to communicate with them because we do not know sign language....” (FGD – Female CHW-002)

3.2.3 Specific objective 3: Availability, accessibility, affordability and quality of rehabilitation services for mothers and parents/caregivers of children with disabilities

Table 18: Availability, accessibility, affordability and quality of rehabilitation services for mothers and children with disabilities

Variable	Physical	Mental	Visual	Hearing	Communication	Multiple	Total
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Access any rehabilitation services							
Any Rehabilitation	93(33.2)	21(31.3)	10(23.8)	4(16.0)	9(42.9)	53(26.2)	190(29.8)
Never	187(66.8)	46(68.7)	32(76.2)	21(84.0)	12(57.1)	149(73.8)	447(70.2)
Nearest Rehabilitation Center							
Less than 1km	22(7.9)	3(4.5)	4(9.5)	1(4.0)	1(4.8)	15(7.4)	46(7.2)
1-5km	26(9.3)	5(7.5)	9(21.2)	1(4.0)	6(28.6)	16(7.9)	58(9.1)
More than 5km	22(7.9)	6(9.0)	2(4.8)	3(12.0)	1(4.8)	15(7.4)	49(7.7)
Don't know	210(75.0)	53(79.1)	32(76.2)	20(80.0)	13(61.9)	156(77.2)	484(76.0)
Rehabilitation services							
regular therapy	42(15.0)	5(5.5)	6(14.3)	5(20.0)	3(14.3)	24(11.9)	85(13.3)
Affordable	40(14.3)	4(6.0)	2(4.8)	6(24.0)	6(28.6)	24(11.9)	82(12.9)
Well equipped	29(46.0)	4(40.0)	1(20.0)	3(37.5)	4(57.1)	18(56.2)	59(47.2)
Face communication challenges	42(15.0)	19(28.4)	11(26.2)	18(72.0)	10(47.6)	56(27.7)	156(24.5)

Overall, 70.2% participants reported that never receive any rehabilitation services and 76.0 % they don't know any rehabilitation center in their community. 84% of study participants with hearing disability never participated in rehabilitation services. This highlights the inadequate of rehabilitation services for women and children with disabilities.

“The challenges we face are that in the Musanze district, we do not have centers to care for people with disabilities, often we need to send them to Rilima (Bugesera), Gahini (Kayonza), Gatagara (Ruhango).... We are very sad because of long distance to get there. We don't have any rehabilitation centers except maybe hospitals delivers some rehabilitation services, but even they can't accommodate everyone and they need to be sent to these centers.” (DMO-001)

“Mothers and children with disabilities encounter with challenges because rehabilitation services are not available and they find treatment difficult due to the long journey travel to the hospital with that services.....” (FGD-Female CHW-001)

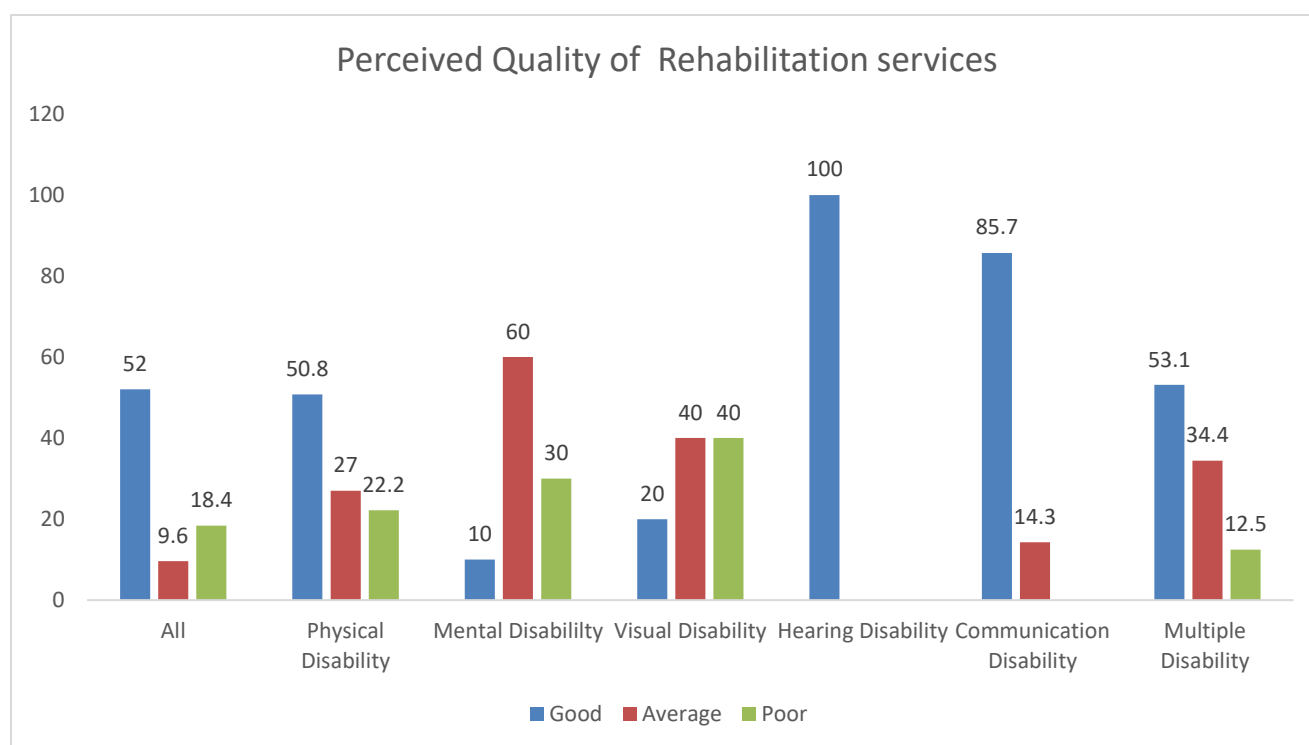


Figure 8: Perceived Quality of Rehabilitation services

Overall, 18.4% reported poor quality of rehabilitation services. 40% of participants with visual disability reported to have received poor quality of rehabilitation services.

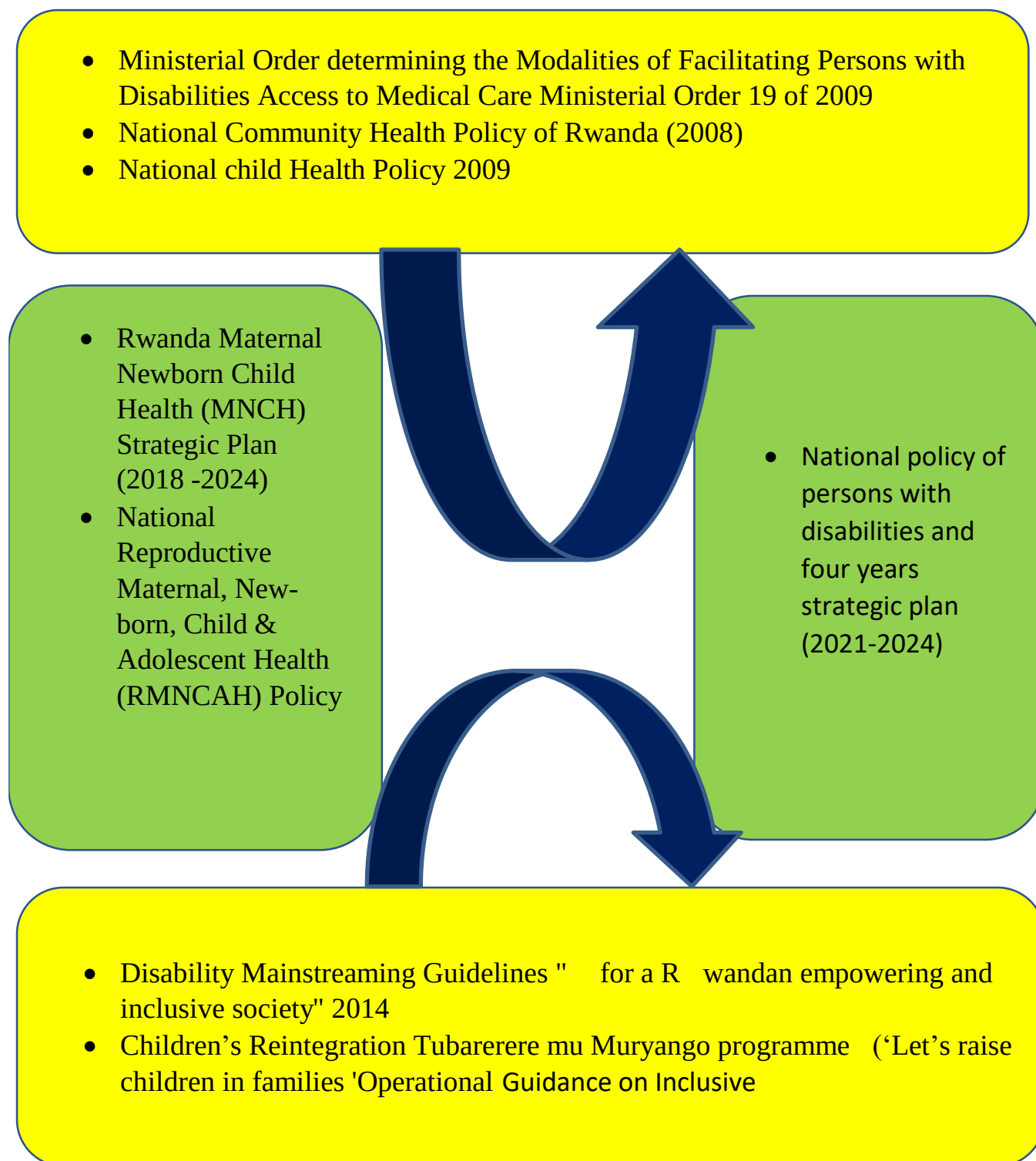
“For rehabilitation services always focus on physical disabilities for rehabilitation tools but they forget these with mental disabilities or invisible disabilities because they need also to get rehabilitation services” (KI – HSMD-003)

“ To the health facilities when they receive someone with eye diseases who seems to get visual disabilities healthcare providers they give him/her services and tell the guide to take him/her home..... I get very sad; the service providers they send them home without having any special discussion with

them which can help them to be rehabilitated. If that rehabilitation services taken before sending them home; that can help them to go back home with a hope of life continuation” (KI – RUB -004)

“Here I can say that rehabilitation services are more expensive where you found that these services are not being covered with their Community Based Health Insurance (CBHI)... even most of people with disabilities are coming in poor families. Even these rehabilitation tools like wheel chair, white cane, ... are not available in our district.....” (KI-Vice mayor in charge of social affair-NYM-001)

3.2.4. Identify deficiencies in existing policies, programs, and services pertaining to maternal, child, and community health as well as rehabilitation



1. Ministerial Order determining the Modalities of Facilitating Persons with Disabilities Access to Medical Care Ministerial Order 19 of 2009

- **Article 4** – Special services for persons with disabilities in order to facilitate persons with disabilities, each District Hospital shall provide special services for persons with disabilities. Any person whose degree of disability is greater than 50% enjoys the privilege of seeing the Doctor first before others. This does not however affect the principle of according priority to seriously ill people [16].

2. National child Health Policy 2009

- This National Child Health Policy was component of the national health policy in Rwanda and an element of health promotion of one vulnerable group. This defined the main guidelines for child health from pre-conception period up to 9 years and covers important issues such as human health of child, the kind of services that should be available and the general rules for their benefit [17].

3. Rwanda Maternal Newborn Child Health (MNCH) Strategic Plan 2018-2024

- This Rwanda Maternal Newborn Child Health (MNCH) Strategic Plan 2018-2024 is consistent with the Global Strategy and existing national policies and strategies, and proposes that health care services should be people-centered, integrated, and sustainable. The emphasis therefore is to ensure that health care is delivered to all persons with quality, equity, and dignity. This will be accomplished through addressing the social determinants of health for women, newborns, and children; ensuring a workforce and health services that are of the highest quality; prioritizing critical health issues; and finally, government accountability for results [18].

4. National Community Health Policy of Rwanda 2008

- Rwanda has developed a National Plan of Action for Orphans and other Vulnerable Children (2006-2011) with participation of children as key stakeholders. The plan seeks to ensure that OVC are able to access education, food, health services, legal support, birth registration, protection from abuse and exploitation through

coordinated efforts by government, NGOs and civil society with full participation of children. Efforts to strengthen community social safety nets for OVC at the district and community levels have been put in place in the form of child mentor associations. The child mentors are chosen by the orphans themselves on the basis of trust and mutual understanding with the mentor. The activity is facilitated by the local authorities. Communities have responded by making bricks or building the shelters for orphans with support from the NGO community. Projects that support orphans and other vulnerable children includes children with disabilities. in the community such small live-stock, vegetable gardens, motor and bicycle taxies and handicrafts. Multi-sectoral, collaborative and coordinated responses are essential for care of orphans and other vulnerable children [19].

5. *Disability Mainstreaming Guidelines "for a Rwandan Empowering and Inclusive Society"*

- These practical suggestions are addressed to any individual or organization active in the health field, including health policymakers, health professionals, organizations supporting or developing health projects, as well as to any other actor in the health field willing to integrate disability into their work. Key areas of activity that can be taken up to overcome these challenges are as follows: Promotion of research and prevention, early detection and early attention. These actions can lessen, or even remove or even prevent the effects of a disability. To promote this, it is essential to foster and apply research in these areas. Implementation of universal accessibility in health environments, processes, and procedures. Providing persons with disabilities with all necessary information in appropriate formats.
- Full accessibility of all services including emergency services.
- Provision of services at reasonable costs (for the specific Rwandan context, expand PWDs needs accommodated through Mutuelle de Sante).
- Promotion of community-based provision of information, advice and training.
- Elimination of communication barriers that currently exist in hospitals and health care services to ensure that disabled patients can communicate in other ways, e.g. sign language or other.
- Simplification of paperwork and ensuring accessibility of administrative procedures for gaining access to health care services.[20]

6. *National policy of persons with disabilities and four years' strategic plan (2021-2024)*

- A number of sectors which impact the welfare of Persons with disabilities are health, education, employment and accessibility. Accessing healthcare in all its forms is challenging for Persons with disabilities because of associated costs, distance from service providers, and systemic and institutional healthcare practices and barriers. Health service access data does not disaggregate by disability which undermines planning and decision making. Eleven of the Sustainable Development Goals (SDGs) require disaggregation by disability. Disaggregated disability data is important if achievements in health care recorded by Rwanda are to be extended to all citizens. In addition, there is little documented evidence about the physical and social barriers that Persons with disabilities may face in accessing health services.
- The present policy is particularly concerned about access to rehabilitation and therapeutic services, assistive aids, and other key health provisions that enable persons with disabilities equal access participation to socio-economic activities [21].

7. *National Reproductive Maternal, New-born, Child & Adolescent Health (RMNCAH) Policy*

The policy states that the ministries and partners identified as key players in the RMNCAH Policy implementation will be:

- MoH committed to strengthen the HMIS ensuring collection and analysis of data disaggregated by age, sex, disability and vulnerability to inform implementation progress.

8. *Children's Reintegration Tubarerere mu Muryango programme ('Let's raise children in families 'Operational Guidance on Inclusive*

- Inclusion of children with disabilities and their families in all aspects of daily life is important because it supports their rights. However, reintegration of children with disabilities from residential institutions does not guarantee the transition from segregation to inclusion. This requires accompanying services and systems such as rehabilitation, inclusive education and others to be in place and for changes in infrastructure, changes in attitudes to adjust social norms and so on. Children with

disabilities do not require different activities or experiences for learning to occur. However, they may need specific, individualized support to benefit from the positive experiences that children without disabilities have access to. For example, adaptations to the built environment/infrastructure (wheelchair ramps), access to assistive devices (a computer with special software for communication), a personal assistant (to help them in the classroom, or to use the toilet at school), habilitation and rehabilitation therapy to support delayed development (physiotherapy, speech therapy, occupational therapy), change in attitude and behavior of the people around them so that they can be involved in day-to-day life, among others.

- Healthcare services that are available are difficult for parents and their children to access due to transport barriers (distance, access, terrain, cost). Nutrition programs and health insurance schemes are designed without the consideration of children with disabilities and their families (e.g., GIRINKA program)[22].

Policies, programs and laws are in place but their implementation is still a major challenge..... To be implemented effectively is that each person changes the perception of how we treat a person with a disability.” (DMO-002)

“Policies are in place and laws are in place but implementation is limits!!! There is nothing to blame our government....., but those laws and policies require to have deep campaigns to ensure that the people knows these , local government officials know.....eee. that's the only thing we have left. because these laws and policies seems to be unknown!!!!!!! The laws are there peee... that's good and yet but have not been able to get it down to being implemented properly.....” (DMO-003)

“Laws and policies for persons with disabilities are well established ... as implementers we also ensure that everyone is aware of them but we are not yet at100%. to ensure that from the national level, district level and community level everyone understand laws and policies for the rights of people with disabilities is one of our priority... from the advocacy for re-innovating buildings for inclusion, training of Healthcare provider, affordability of services to all levels , what is better now there is great changes of community members behaviors compared to the past” (KI-RBC-002)

“In our community Nutrition program/interventions, we take special care to children with disabilities for them they are enrolled and stay in the nutrition program for five years we also ensuring how the report for children received healthcare services can be reported per disaggregate per disabilities.” (KI-NCDA-001)

“To ensure proper implementation of laws and policies, there is a need to include persons with disabilities from planning, implementation, monitoring, and development of interventions in the community” (KI- DMO-001).

Conclusion

The study revealed that mothers and parents/caregivers of children with disabilities shared many barriers to access to maternal Child health, community health and Rehabilitation services. Some of the Maternal, Newborn and Child health services were inaccessible at the health facility. Near half of mothers and children with hearing disability had difficulty to access maternal child health (MCH) services while seeking care. Furthermore, 35.9% of total participant indicated that they received poor quality of service during their Maternal Child Health (MCH) care services, 31.6% incomplete continuum of maternal and newborn healthcare. Mothers with visual and hearing disability were more likely to have incomplete continuum of maternal and newborn care.

The mothers with visual disabilities inaccessible information's printed in braille. Mothers and children with hearing impairments raised concerns of challenges in communication with healthcare providers as well as lack of privacy during consultations as they often accompanied with sign language interpreters. Mothers and parents/caregivers of children with physical disability raised barriers regarding buildings with many stairs as well as beds that are not adjustable. Also, study findings shown that some of study participants encounter with communication barriers during accessing healthcare services among community health workers.

However, they also face a series of additional barriers to rehabilitation services (transportation, access to rehabilitation services, high cost) that further increased inaccessibility of services for them. and resources affects both groups, while providers' inadequate knowledge and skills to address the special needs of mothers and children with disabilities. The limited healthcare and disability services available for mothers and children with disabilities, especially in rural areas may prevent children from receiving early interventions and treatment. Even with community-based health insurance, many services are not covered (e.g., physiotherapy, orthopaedical, assistive devices) and are beyond the financial means of the family. In addition, RMNCH policies are there but most of participants highlighted implementations barriers which is needed to be strengthened.

Recommendations

Recommendation to Ministry of Health and Rwanda Biomedical Center

- Ministry of health need to develop a special protocol for treatment of patients with disabilities especially mothers and children with disabilities.
- Re-innovating health facilities buildings including health post, health centers and hospitals to ensure disability inclusion. New health facilities under construction should be monitored to ensured disability inclusion.
- Upgrading infrastructures to improve accessibility including adjustable beds in women delivery rooms for inclusivity
- Having staff specializing in disability care at the health facilities is crucial to advance healthcare services.
- Integrate disability inclusion services among health care providers including community Health workers such sign language and includes it's in school so that healthcare providers graduate with sign language proficiency
- Equipping healthcare providers with disability inclusion skills to ensure a more proactive and inclusive approach in services provision.
- Health care providers including community health workers should receive comprehensive training on early detection of disabilities especially among children
- Ensure usual availability of rehabilitation tools like wheel chair and walking aids, hearing and communication devices, white cane, artificial limbs and surgical appliances ... to the hospital for quick support to everyone with special care
- Rehabilitation facilities for people with disabilities need to be increased at health centers to ensure that they can access services closer to their homes without burden of traveling for long distance to the hospitals.
- Ensure that HMIS data are disaggregated per type of disability

Ministry of Finance

- Resource allocation for rehabilitation services; it is essential to ensure that adequate budgetary resources are allocated specifically for rehabilitation services targeting people with disabilities.
- Dedicated funding allocation especially to the district level to make consistent funding's for persons with disabilities healthcare services
- Support the procurement necessary equipment's that meet diverse needs of people with disabilities

Ministry of Local Government

- The ministry of local Government and its partners should focus on improving the socio-economic status of mothers and children with disabilities by creating income-generating opportunities through making small cooperatives or saving groups.

National Child Development Agency (NCDA)

- Reporting for children received healthcare services including nutritional program must be disaggregate per disability with each type of disability among all healthcare providers including Community Health Workers (CHWs)

General Recommendation for all policy makers

- Provide adequate disability inclusion training and conduct regular monitoring for policy implementation
- Comprehensive training on disability related policies, programs and rights should be provided to community members, local authorities, healthcare providers and program implementers
- Prioritizing establishing more rehabilitation centers to reduce the burden of long-distances travel for individuals who currently need to go to referral hospital like Rilima, Gatagara and Gahini.....

Recommendations to healthcare institutions and healthcare providers including community health workers

- Health facilities should incorporate sign demonstrations to assist patients with hearing and speaking disabilities. Many individuals with these disabilities may not be able to read and rely on these demonstrations to understand health facilities rooms for the services.
- Healthcare providers need to ensure reasonable accommodation to their patients; as necessary and appropriate changes or adjustments made, without causing excessive difficulty or burden, to ensure that people with disabilities can fully and exercise their rights equally with others.
- Healthcare providers modifying rules, practices, conditions or requirements to address the specific needs of individuals with disabilities, allowing them to make their own decision.
- Healthcare providers establishing a dedicated time for visiting and engaging with people with disabilities.
- Among community health workers there could be engaged one with disability so that people with disabilities can get an advocacy from him/her and they can also be open to her rather than someone without disabilities.
- Rehabilitation services should adopt a holistic approach that goes beyond providing physical tools and aids. It is crucial to address the mental and emotional wellbeing of individuals undergoing rehabilitation. This can include offering physiological counseling, peer support programs and mental health therapies that help individuals cope with emotional and psychological challenges associated with their conditions.
- Health facilities can be responsible to report a disaggregate per disability during recording patient's identification this can help to know the number of persons with disabilities in services attendances like: Antenatal care services, maternal newborn and child health services, community health services, sexual reproductive health and right programs, nutrition's programs, ...
- Ensuring information's available in accessible formats like: braille, clearly printed formats....

Recommendation to non-government organization implementing to RMNCH and community Health services

- Institutions representing People with disabilities should give a voice in community-based meeting (Inteko z'abaturage) these institutions should actively participate, learn from community members, help people with disabilities know available healthcare services among community health workers and health facilities and share community members care and right of people with disabilities.
- NGOs need more visits persons with disabilities within the moments these community members specifically persons with disabilities they can raise their challenges and barriers during accessing both maternal child health and community health services and the sit together to find solution.
- Strengthen partnership with government institutions, private sectors and other partners to ensure closely working together for more advocacy to RMNCH, community health and rehabilitations services for persons with disabilities.
- Engage in policy dialogues to push for reforms that makes healthcare services accessible for person with disabilities.
- Mobilize resources from donors, foundations and private sectors to ensure availability of funds for RMCH services among person with disabilities.
- Implement behavior changes campaigns among community members. This will help to develop positive attitudes towards persons with disabilities and removal of barriers and challenges related to services accessibility.

Recommendations to Academics including Universities and research institutions

- Conduct operational researches related to practices and barriers for person with disabilities during accessibility of Reproductive Maternal Newborn Child Health and community health services for more documentations for data-based decision making.
- Promote multi- sectoral research collaboration with NGOs for advocacy through research to establish barriers and challenges persons with disabilities encounter with during accessing RMNCH, community health and rehabilitation services.
- Integrate disability inclusion in curriculum, to ensure everyone graduated with basic skills related disability inclusions.
- Disseminations of findings to ensure that results reach to policy makers, program implementers and the public itself.

Recommendations to Media and communications users

- Engage persons with disabilities in using digital platforms to promote the use of maternal health services
- Work with organizations of persons with disabilities when preparing health related contents.
- Use radio dramas, TV shows and theater to spread information related to available maternal, child health services at health facilities and in the community

References

1. WHO, *Global report on health equity for persons with disabilities*. <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>, 2022.
2. UN, *United Nations: Department of Economic and Social Affairs (DESA): INCLUSIVE HEALTH SERVICES FOR PERSONS WITH DISABILITIES*. 2023.
3. UN, *Convention on the Rights of Persons with Disabilities (CRPD)* <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd>, 2006.
4. UN, *United Nations (2015) Transforming Our World: The 2030 Agenda for Sustainable Development*. New York, NY: United Nations. 2015.
5. UN_Women, <https://www.unwomen.org/en/digital-library/publications/2018/12/the-empowerment-of-women-and-girls-with-disabilities>. 2018.
6. NISR, *National Institute of Statistics of Rwanda (NISR); The Fifth Rwanda Population and Housing Census, Main Indicators Report, February 2023*. 2023.
7. McCoy, L., & Theobald, S., "Barriers to healthcare access in rural areas: A systematic review." *International Journal for Equity in Health*, 16(1), 1-12. doi:10.1186/s12939-017-0590-5 2017.
8. WHO, *World Health Organization. "Access to health services." In World Health Statistics 2015. Retrieved from WHO*. 2015.
9. Signore, C., et al., *Pregnancy in women with physical disabilities*. *Obstet Gynecol*, 2011. **117**(4): p. 935-947.
10. Mitra, M., et al., *Antenatal Hospitalization Among U.S. Women With Intellectual and Developmental Disabilities: A Retrospective Cohort Study*. *Am J Intellect Dev Disabil*, 2018. **123**(5): p. 399-411.
11. Mitra, S., A. Posarac, and B. Vick, *Disability and Poverty in Developing Countries: A Multidimensional Study*. *World Development*, 2013. **41**: p. 1-18.
12. Hosseinpoor, A.R., et al., *Socioeconomic inequality in disability among adults: a multicountry study using the World Health Survey*. *Am J Public Health*, 2013. **103**(7): p. 1278-86.
13. Anderson, P. and R. Kitchin, *Disability, space and sexuality: access to family planning services*. *Soc Sci Med*, 2000. **51**(8): p. 1163-73.

14. UPHLS, *BASELINE SURVEY ON SOCIAL INCLUSION, ATTITUDES AND ACCESS TO SRH SERVICES FOR PERSONS WITH DISABILITIES*. 2019.
15. Meara, J.G., et al., *Global Surgery 2030: evidence and solutions for achieving health, welfare, and economic development*. The Lancet, 2015. **386**(9993): p. 569-624.
16. GoR, *Government of Rwanda: Ministerial Order determining the Modalities of Facilitating Persons with Disabilities Access to Medical Care Ministerial Order 19 of 2009*. 2009.
17. MIGEPROF, *National child Health Policy 2009*. 2009.
18. RBC, *Rwanda Maternal Newborn Child Health (MNCH) Strategic Plan 2018-2024*. 2018.
19. MoH, *National Community Health Policy of Rwanda 2008*. 2008.
20. NCPD, *Disability Mainstreaming Guidelines "for a Rwandan Empowering and Inclusive Society"*. <https://www.ncda.gov.rw/index.php?eID=dumpFile&t=f&f=23899&token=79daf0bd824c0801fac7c5fc4d492c824c1903d6>, 2014.
21. MINALOC, *National policy of persons with disabilities and four years' strategic plan (2021-2024)*. https://www.minaloc.gov.rw/fileadmin/user_upload/Minaloc/National_Policy_on_Disability_and_Inclusion_final.pdf, 2021.
22. NATIONAL_CHILD_DEVELOPMENT_AGENCY, *Operational Guidance on Inclusive Children's Reintegration*. <https://www.unicef.org/rwanda/media/3211/file/Operational%20Guide%20.pdf>, 2021.