Republic of Rwanda
Ministry of Local Government

NATIONAL COUNCIL FOR PERSONS WITH DISABILITIES

Knowledge, Attitudes and Practices (KAP) study on children with disabilities living in families and institutions in Rwanda

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Republic of Rwanda
NATIONAL CHILD DEVELOPMENT AGENCY

hope and homes for children

UNIVERSITY OF RWANDA

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FOREWORD

This "Knowledge, Attitudes and Practices (KAP) study on children with disabilities living in families and institutions in Rwanda" was jointly led by The National Council of Persons with Disabilities (NCPD), The National Child Development Agency (NCDA), and Hope and Homes for Children (HHC). A tripartite Memorandum of Understanding has been signed between these Government Agencies and Civil society Organization to jointly invest in supporting the transformation of Rwanda's childcare and protection system into a family-based care system. With the technical support from the University of Rwanda, this partnership was instrumental in the conception and successful realization of this study.

We all believe that the rights of persons with disabilities, to live in a family within their communities and be given equal opportunities and freedom of choice like other citizens, which is at the heart of the Convention on the Rights of Persons with Disabilities (CRPD), can only be achieved if states invest in ensuring that citizens with disabilities have access to in-home and community-based provisions from the early stages of their lives. Like all signatory states, Rwanda is fully committed to the rights of children with disabilities, including their inclusion in neighbourhood schools and rights in families and communities. In addition, Rwanda has adopted the National Strategy for childcare reform to ensure this right is respected. A recent study showed however that more than 2000 children with disabilities are still being cared for in residential centers.

The present study demonstrates the knowledge, attitudes, and practices prevailing among community members and professionals regarding children with disabilities in families and in institutions. The report reveals the extent and content of a mistaken belief that it is too difficult to deinstitutionalize children with disabilities due to insufficient local and family capacity, a belief that is behind most cases of institutionalization. On the other hand, the report provides evidence that many community members still believe that with appropriate support, children with disabilities can fully enjoy their rights with respect to family life.

The success of this survey was made possible by a number of organizations and individuals. We thank the UK aid from the UK Government for their financial support. We are thankful to Dr. Epaphrodite Nsabimana (HHC), Emmanuel Murera (NCPD), Marcel Nkurayija (NCPD), Florentine Uwamaliya (NCPD), Ange Marius Uwurukundo (NCDA), Brigitte Hitimana (HHC), and Jacques Mucyuranyana (HHC) to have coordinated this study at all its stages.

Prof. Darius Gishoma (UR), Prof. Evariste Karangwa (UR), Dr. Benoite Umubyeyi (UR), and Mr. Bosco Bigirimana (UR) for the execution of this study. Also, we would like to thank parents and caregivers who gave their time to participate in this study. They provided information, without which the completion of this study would not have been possible. We extend special thanks to the key informants who recognized the need to provide the essential information through interviews. These included leaders of residential centers for children with disabilities, local professionals (social workers and psychologists), and community leaders involved in the gatekeeping mechanism to prevent family separation, especially families of children with disabilities. Our sincere gratitude goes to the Institutional Review Board of the College of Medicine and Health Sciences that reviewed the protocol and provided the ethical clearance for this research. In particular, we acknowledge the contribution of the research assistants who collected data and contributed towards the success of the exercise in general. As we are not able to attribute every individual in this report, we appreciate the support and collaboration provided by all stakeholders.

We call for a collective effort of different stakeholders, including Government and Non-Government Organisations, the private sector, international agencies, and other development partners to use this report in informing their decisions and plans.

NDAYISABA Emmanuel

Executive Secretary
National Council for Persons with Disabilities

EXECUTIVE SUMMARY

Background

The rights of persons with disabilities, to live in a family within their communities and be given equal opportunities and freedom of choice alike other citizens, is at the heart of the Convention on the Rights of Persons with Disabilities (CRPD). However, this can only be achieved if states invest in ensuring that citizens with disabilities have access to in-home and community-based provisions from the early stages of their lives (Márton et al., 2013).

Like all signatory states, Rwanda is fully committed to the rights of children with disabilities and other special educational needs, including their inclusion in neighbourhood schools and rights in families and communities (Republic of Rwanda 2013, NCC 2012). However, despite existing policies and legislations geared toward these commitments, reports continue to highlight challenges hindering children with disabilities' access to their rights in many countries, including Rwanda (UNICEF, 2018). For this reason, Hope and Home for Children, in collaboration with UK Aid Match, the National Council of Persons with Disabilities (NCPD) and the National Commission for Children (NCC), now NCDA, have jointly been investing in supporting the national integration program of children with disabilities in families and preventing their separation.

The study

This study is part of the response to the global call for the provision of quality alternative family-based care and prevention of family separation for children with disabilities. The study is premised on the view that the knowledge, attitudes, and practices regarding the attributes assigned to, and the conceptualization of, children with disabilities in their families and communities, vis-à-vis institutional care for children with disabilities, are also crucial determinants of barriers/enablers of full and meaningful integration of children with disabilities into community life in Rwanda.

To achieve this objective, a cross-sectional analytical design using both quantitative and qualitative approaches was conducted between October and November 2020. A survey questionnaire (quantitative data) was filled out by parents and caregivers of children with disabilities to evaluate their Knowledge, Attitudes, and Practices (KAP) regarding children with disabilities and deinstitutionalization. To understand parents' experiences, a subsample of parents and caregivers participated in focus group discussions. In addition, qualitative interviews were undertaken with leaders of residential institutions for children with disabilities, local professionals (social workers and psychologists), and community leaders involved in the gatekeeping of children with disabilities.

A total of 807 caregivers/parents of children with disabilities completed the questionnaire, 17 parents/caregivers attended the focus group discussions, and ten professionals working with children with disabilities were individually interviewed.

Key Findings

Prevalence of disability

A total of 2,258 children aged 2-17 years old were listed in 807 households. Out of these children, 38% were reported to have some form of disability, while 62% did not have any type of disability. The common types of disability were a physical disability (34.7%), multiple disabilities (24.2%), a mental and intellectual disability (20.2%), a visual disability (7.9%), a speaking disability (5.2%), a hearing and eyesight disability (3.6%), a hearing and speaking disability (1.4%), a hearing disability (1.4%), and a skin condition (1.2%).

Experience of living in a residential institution

Regarding any child with disabilities in the family, only 5.1% of participants reported that their child with disabilities has ever lived in a residential institution full-time. Only 2.1% mentioned their child with disabilities to be living full-time in a residential institution during the survey.

Attributes and conceptualization of children with disabilities

The results showed that there were more negative attributes assigned to children with disabilities compared to positive ones. 79.9% of all first reported attributes ascribed to children with disabilities were classified by parents as negative, while only 18.8% were classified as positive. Parents/caregivers were requested to list three relevant emotions (feelings that they experience when they see, meet, or think about their child with disabilities). 72.6% first reported extremely negative feelings while only 22.8% of feelings were positive.

Awareness about the rights of, and services for, children with disabilities

In terms of awareness of the rights of children with disabilities, 88.7% of the respondents agreed that they were aware of children with disabilities' rights as having the same opportunities as everybody else; 93.3% were aware of their right to attend school, 93.7% were aware of their right to the best possible healthcare, and 96.2% were aware of their right to not be hurt or mistreated. About 63.2% of participants were unaware of any legislation that seeks to protect or extend support services to children with disabilities.

Attitudes towards the deinstitutionalization of children with disabilities

This survey suggests that parents and caregivers generally have a positive attitude towards the deinstitutionalization of children with disabilities. Overall, 82.6% of participants agree with the assertion *"I believe we should transition from institutional care to family and community-based alternatives."* Similarly, 90.7% of participants agree with the statement *"I would consider raising my children with disabilities in the family."* Parents and caregivers are aware of the advantages of raising children with disabilities in their families and communities. They also identified some disadvantages of raising children with disabilities in an institution. The most frequently reported disadvantages are:

- Lack of parental love (38.9%).
- Separation of children with

disabilities from his/her family (34.7%).
- Lack of education and increased risk of acquiring bad behaviors (28.1%).

Other disadvantages include not being cared for as much as a parent would (27.6%), children with disabilities feeling uncomfortable with substitute caregivers (24.9%), growing up without knowing the family members (16.2%), risk of violence or harassment from some educators/ caregivers (14%), living as an orphan (6.3%), and living as if they are in quarantine (2.5%).

Attitudes regarding residential institutions caring for children with disabilities and intention to use a childcare institution

Parents and caregivers emphasized that rearing a child solely with a disability in the family can be very challenging, mainly because they lack inclusive and friendly services for children with disabilities in their communities. Paradoxically, 76.3% of the participants hold a favourable attitude towards institutional care, mainly due to the support offered to children with disabilities regarding education, medical care, and nutrition.

Integration of children with disabilities into community life

More than half of the participants reported that their child with disabilities participates in household activities (53.2%). In comparison, 46.8% said they do not allow their child with disabilities to participate. 65.8% of participants reported their child with disabilities to play with other children within the family. More than half of participants said that their child with disabilities attends family events such as weddings (50.3%), and 61.3% said their child with disabilities participates in religious services with others. 54% of participants reported that their child with disabilities does not attend school. The most reported reason for not attending school was that the family could not afford the fees to send the child to school (44.2%), followed by the school not letting the child go because of her/his disability (37%). The mother was reported as the most common primary caregiver who stays at home with the child (33%). The family was declared as the primary source of support and services concerning children with disabilities (57.4%).

Barriers to effective integration of children with disabilities into community life

A family's economic capacity

Regarding parental and family capacity to provide care to children with disabilities, 76.6% of participants agreed that their family lacks the ability (financial, material, and human resources) to take care of children with disabilities within the family. Also, 63.3% of participants reported that raising a child with disabilities in the family is a burden. In comparison, 66.5% of participants thought that raising a child with disabilities in a family requires one parent to stop working to take care of him/ her.

Availability and cost of services for children with disabilities

Regarding availability and the price of community-based services compared to services provided to children with disabilities in residential institutions, most participants (77.2%) reported there to be no inclusive schools within the community to accommodate children with disabilities when they come to live in the family.

Stigmatization
81.2% of participants agreed that where they live, children with disabilities are called abusive names and treated in a way that undermines their dignity and makes them worthless community members compared to their peers without disabilities. Moreover, 48.9% of participants agreed that some family members could not even stay with a child with a disability. In comparison, 41% reported that their families are embarrassed or ashamed to have a child with a disability at home.

Recommendations

The study recommends that all relevant partners deinstitutionalizing children with disabilities should prioritize the reintegration of children into their families and communities and consider a community-based strategy. Such a strategy should cautiously interlink empowering the families and communities of children with disabilities through appropriate information and/or provisions (services and resources) whilst also fostering their social and economic development. However, given the complex social systems families live in, an accurate understanding of the socio-economic contexts within which local capacities and resources for children with disabilities are mobilized and made to benefit them is key to setting and achieving the desired deinstitutionalization goals.

1. INTRODUCTION

1.1. Background

The Convention of the Rights of Persons with Disabilities affirms the rights of persons with disabilities to live in the community, with choices equal to others. The State should ensure all persons with disabilities have access to in-home, residential, and other community support services, including personal assistance necessary to support living and inclusion in the community without isolation or segregation (Márton et al., 2013). Disability among children is a prevalent problem in Africa but is seldom recognized and often deliberately hidden. Children with disabilities face social, political, and economic barriers that harm their physical and mental development. The vast majority of these children receive no education; they are absent from school data sets and invisible on the national policy agenda. (Deluca, Tramontano, Cole, & Kett, 2017)

Often considered a curse on their families, they are discriminated against and stigmatized at home, in schools, in residential institutions, and in the community. Children with disabilities are probably the most neglected group in both the policy domain and the private sphere. They are absent or referred to only marginally in public policy documents, sectoral (health, education, social) development plans, and poverty reduction programs. National plans of action for children in African countries sometimes refer to children with disabilities but suggest little effort to meet their needs. (Lakhan & Sharma, 2010)

In Rwanda, the Government has made a significant commitment to the rights of children with disabilities, including ratifying the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2008 and establishing the National Council for People with Disabilities (NCPD). The latter acts as an advocacy body to coordinate activities and monitors progress towards this commitment. Rwanda has laws and policies that allow for the inclusion of children with disabilities in education, reflected in the Education Sector Strategic Plan (ESSP) 2018/19 to 2023/24. (UNICEF, n.d.). The National Commission for Children, now NCDA, also implements several activities to ensure the needs of children with disabilities are met, including their reintegration into the community when separated from family members. However, a recent evaluation highlighted persistent stigma against children with disabilities in the community and households (UNICEF, 2018).

1.2. Rationale and Purpose of Study

Global recommendations outline that children with disabilities must be at the heart of successful childcare reform efforts in countries that want to prevent family separation and provide quality alternative family-based care. As such, Hope and Home for Children, in collaboration with UK Aid Match, the National Council of Persons with Disabilities, and the National Commission for Children, now NCDA, mobilized funds to support the implementation of a program to reintegrate children with disabilities and prevent family separation. However, little is known about the knowledge, attitudes, and practices regarding children with disabilities, the use of institutional care for children with disabilities, and the barriers/enablers for the complete and meaningful integration of children with disabilities into community life in Rwanda.

Hope and Homes for Children (HHC), in collaboration with the National Council for Persons with Disabilities, and the National Commission for Children, now National Child Development Agency, conducted a KAP study from October to November 2020. The aim was to gain recent and complete information on Knowledge, Attitudes, and Practices (KAP) regarding children with disabilities and deinstitutionalization. The study aims to inform efforts towards the inclusion of children with disabilities in Rwanda's national plans for childcare reform and ensure no one is left behind.

1.3. Objectives of the Study

1.3.1. General objective

The overall objective of this study was to assess the Knowledge, Attitudes, and Practices (KAP) regarding children with disabilities and deinstitutionalization in districts with and without residential institutions for children with disabilities in Rwanda. The results are expected to build an evidence base that will inform HHC and policymakers about actionable recommendations to support deinstitutionalization and improve the wellbeing of children with disabilities.

1.3.2. Specific objectives

The specific objectives of the study are as follows:

- To evaluate the current Knowledge, Attitudes, and Practices (KAP) of parents of children with disabilities regarding the attributes and conceptualization of children with disabilities.
- Evaluate KAP of parents of children with disabilities regarding the use of institutional care for children with disabilities and the integration of children with disabilities into community life.
- Explore possible relationships between the conceptualization/attributes of children with disabilities, the use of institutional care for children with disabilities, and the integration of children with disabilities into community life.
- Examine the barriers/enablers for the full and meaningful integration of children with disabilities into community life.
- Explore perspectives among leaders of residential institutions for children with disabilities and local professionals (social workers and psychologists) regarding the deinstitutionalization of children with disabilities in Rwanda.
- Provide general recommendations based on the main findings of the study.

2. METHODOLOGY

2.1 Study Design

This study used a cross-sectional analytical design with both quantitative and qualitative approaches. Between October and November 2020, a survey questionnaire (quantitative data) was carried out with parents and caregivers of children with disabilities to evaluate their Knowledge, Attitudes, and Practices (KAP) regarding children with disabilities and deinstitutionalization. To gain the breadth and depth of parents' experiences, a sub-sample of parents and caregivers participated in focus group discussions. In addition, qualitative interviews were undertaken with leaders of residential institutions of children with disabilities, local professionals (social workers and psychologists), and community leaders involved in the gatekeeping of children with disabilities.

As part of assessing the knowledge, attitudes, and perceptions of family and community members towards children with disabilities, a qualitative approach was used to complement the quantitative design. The qualitative approach used individual interviews with different professionals and stakeholders working with children with disabilities and their families as well as focus group discussions with parents of children with disabilities. Quantitative and qualitative approaches used different methods of data collection and analysis. Thus, the researchers presented qualitative and quantitative results simultaneously to enrich the analysis and interpretation of findings. This helped to maintain coherence in the discussion of key findings as the use of both methods provided complementary insights, and qualitative data permitted triangulation and confirmation of survey findings from quantitative methods.

The sample size was calculated by using the formula: $N= Z^2 P (1-P)/e^2$
Where:

- N= sample size,
- Z= level of confidence,
- P= baseline level of the selected indicator
- and e= margin of error.

Given that the baseline level of the selected indicator was unknown (it was assumed to be at 50%=0.5; recommended when P is unknown), Z= 1.96 (at 95% confidence interval), e= 0.05,

The estimated sample size was:

$$n= \frac{1.96^2 x0.5(1-0.5)}{0.05^2}=384$$

Adjusting for:
Number of domains = 2 clusters (district with and without residential institutions for children with disabilities)

The estimated required sample size was therefore adjusted for design effect and domains: N = 384 * 2= 768

Assuming a non-response rate of 10%, the final sample size was therefore adjusted upward to: N = 768+ (768* 10%)= 845

The sample size was rounded up to

845 parents of children with disabilities.

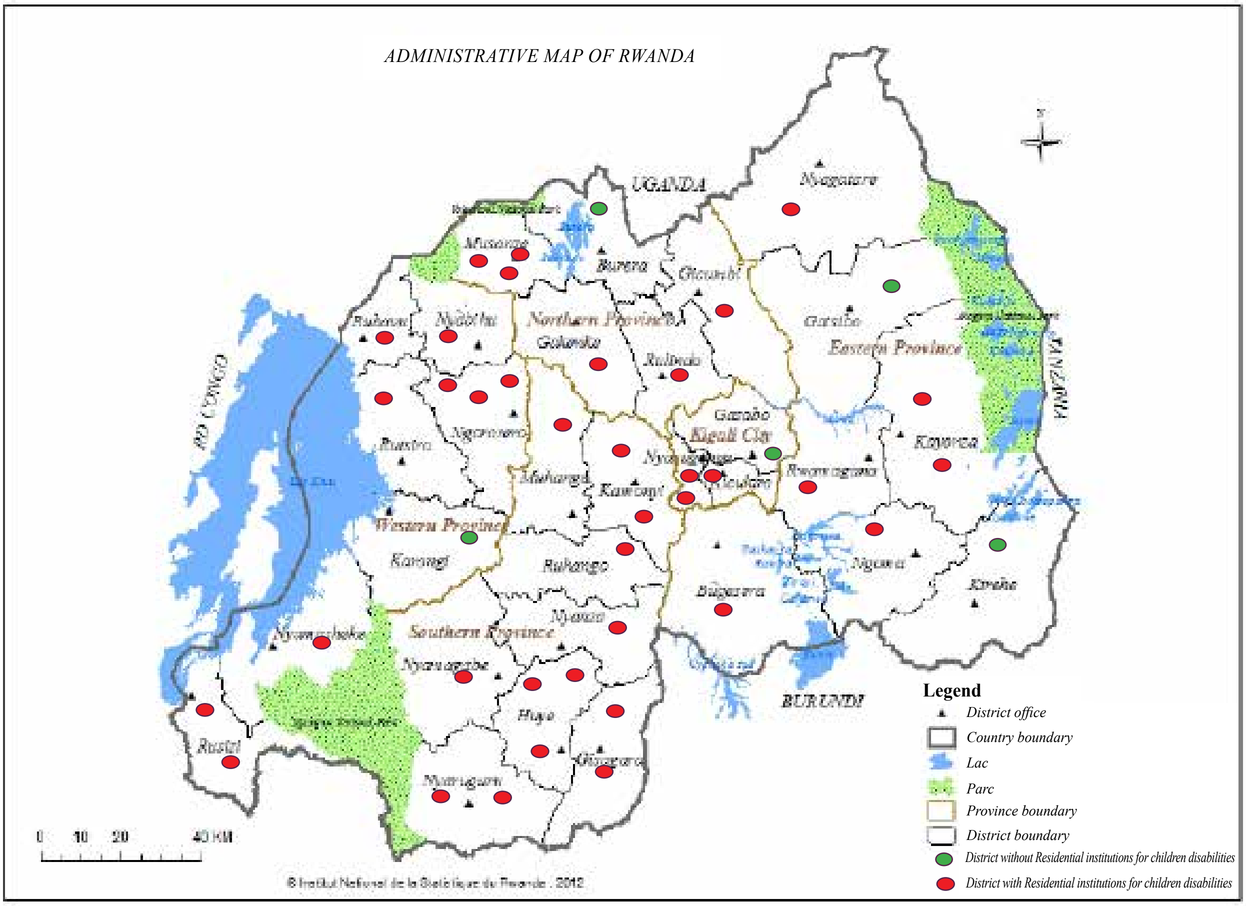

Figure 1: Spatial distribution of residential institutions for children with disabilities

2.2 Selection of Participants

The first stage of selecting the specific sample was based on a stratified multi-stage sampling design. In this stage, the sample size of 845 was allocated to two main categories, considering the spatial distribution of residential institutions for children with disabilities (see Figure 1): a) districts with residential institutions for children with disabilities, and b) districts without residential institutions for children with disabilities.

Only five districts (20% out of 30 communities) do not have residential institutions for children with disabilities, and every province except the Southern Province has at least one district without a residential institution for children with disabilities (Kirehe and Gatsibo from the Eastern Province, Karongi from the Western Province, Burera from the Northern Province and Gasabo for the City of Kigali). The study investigators selected all five districts without residential institutions for children with disabilities and 5 out of 25 districts with residential institutions for children with disabilities.

The second stage involved the selection of two sectors per district (20 sectors from 10 districts). Sectors were selected following the criteria below:

- Presence of residential institution for children with disabilities. In each of the five districts with residential institutions for children with disabilities, the study team identified in every district; a) one sector housing the residential institution for children with disabilities and b) one other sector randomly selected among two sectors with a high number of PWDs in the district (total = ten sectors)

- For the two districts without residential institutions, only a high number of PWDs was considered (total= ten sectors).

About 17% of respondents were from urban households and 83% from rural households, reflecting the overall national urban-to-rural ratio (National Institute of Statistics of Rwanda, 2015). Thus, from the 20 sectors, at least four sectors are urban (3 urban sectors within districts with residential institutions for children with disabilities and one urban sector in a community without residential institutions for children with disabilities).

The research team aimed to select two cells from each sector. However, researchers felt that it would be challenging to find the required number of households with children with disabilities in such a limited area. It was therefore agreed that the unit of investigation be limited to sector level. According to the count of the resident population aged five years and above with disabilities per sector, conducted by the NISR in 2014, the lowest number of PWDs per sector was found in Rwezamenyo (Nyarugenge District) with 336 PWD; the highest number was found in Rugarama sector (Gatsibo District) with 2,386 PWD. Given that children and adolescents aged between 5 and 19 years represent 19.42% of the total population of PWDs, we can expect the total number of children with disabilities per sector to be between 65 and 463.

In the third stage, the task in every sector was to select the households with children with disabilities to involve in the study. With support from the person in charge of social affairs and NCPD coordinators at sector level, a list of households with children with disabilities was provided. Households were randomly, proportionately sampled based on the estimated population size of children with disabilities per sector. On average, 27 households were sampled per sector, and caregivers (parents or guardians) were invited to be interviewed.

Based on the Fourth Population and Housing Census, Rwanda, 2012, the districts profile is Nyamirambo (urban 100%), Muhoza (urban 81.9%), Kigabiro (55 %), and Remera (100 %).
In addition, the selection of participants for group discussions followed a purposive sampling strategy to recruit participants in both individual and focus group discussions. The choice of participants in the focus groups was facilitated by the staff of Hope and Homes for Children.

Table 1: Distribution of sample

	Province	District	Sector	Total PWD	Estimated population children with disabilities 5-19 years of age	Sampled
With residential institutions for children with disabilities	Kigali	Nyarugenge	Nyamirambo (Urban)	1044	203	19
			Kanyinya	1 057	205	20
	North	Musanze	Muhoza(Urban)	1152	204	19
			Gataraga	1048	204	19
	Eastern	Rwamagana	Kigabiro(Urban)	899	175	17
			Mwulire	946	184	18
		Nyagatare	Gatunda	1078	210	20
			Karangazi	2155	419	40
	Southern	Nyanza	Mukingo	1280	249	24
			Nyagisozi	1165	226	22
		Kamonyi	Gacurabwenge	1452	282	27
			Musambira	2072	402	39
	Western	Ngororero	Matyazo	1287	250	24
			Ngororero	1746	339	32
		Nyabihu	Mukamira	1,268	246	23
			Karago	1,727	335	32
Without residential institutions for children with disabilities	Eastern	Gatsibo	Kabarore	2366	459	44
			Rugarama	2,386	463	44
	Kigali	Karongi	Remera (Urban)	1425	277	26
			Kinyinya	1,680	323	31
Total				**28176**	**5655**	**540**

2.3 Survey Instruments

Trained research assistants visited households in each of the selected sectors and completed the survey tool with the respondents using a 1:1 interview in the local language. The questionnaire explored:

- **Socio-demographic information**: the initial section of the tool gathered information to identify the location of the respondent and other demographic information.

- **Type of disability**: using the Washington Group questions, the study team collected information regarding children and their disability type.

- **Attributes & conceptualization of children with disabilities**: to assess the perceptions of respondents associated with children, the study used a psychometrically validated open-ended approach in which participants were asked to consider the attributes they associated with a) a child with disabilities and b) a typical child (Shelton et al, 2018). Using a Likert scale, participants were invited to decide for each characteristic whether it was positive, negative, or neutral. Scores obtained were averaged across the listed attributes to provide an overall score of attributes favorability for both children with disabilities and children without disabilities.

- KAP regarding the use of institutional care and deinstitutionalization: all respondents were asked questions on their knowledge, attitudes, and practices regarding children with disabilities, the use of institutional care and deinstitutionalization. A Likert scale was used to gather attitudinal data across five domains: society and support, personal attitude towards disability, the contribution of children with disabilities to society, education and inclusion, and protection.
- Barriers/enablers of the full and meaningful integration of children with disabilities into community life: the study explored the following four main areas: a) understanding and adherence to the practice of abolishing residential care facilities for children with disabilities, b) parental and family capacity to provide care to children with disabilities, c) availability and affordability of community-based services, d) stigma.
- Impact of Covid-19: the study explored the perceived effects of COVID-19 on a) families with children with disabilities, b) on the care of children with disabilities, and c) the anticipated effects of COVID-19 on the deinstitutionalization program for children with disabilities.

The KAP survey on children with disabilities in Rwanda explored the following domains

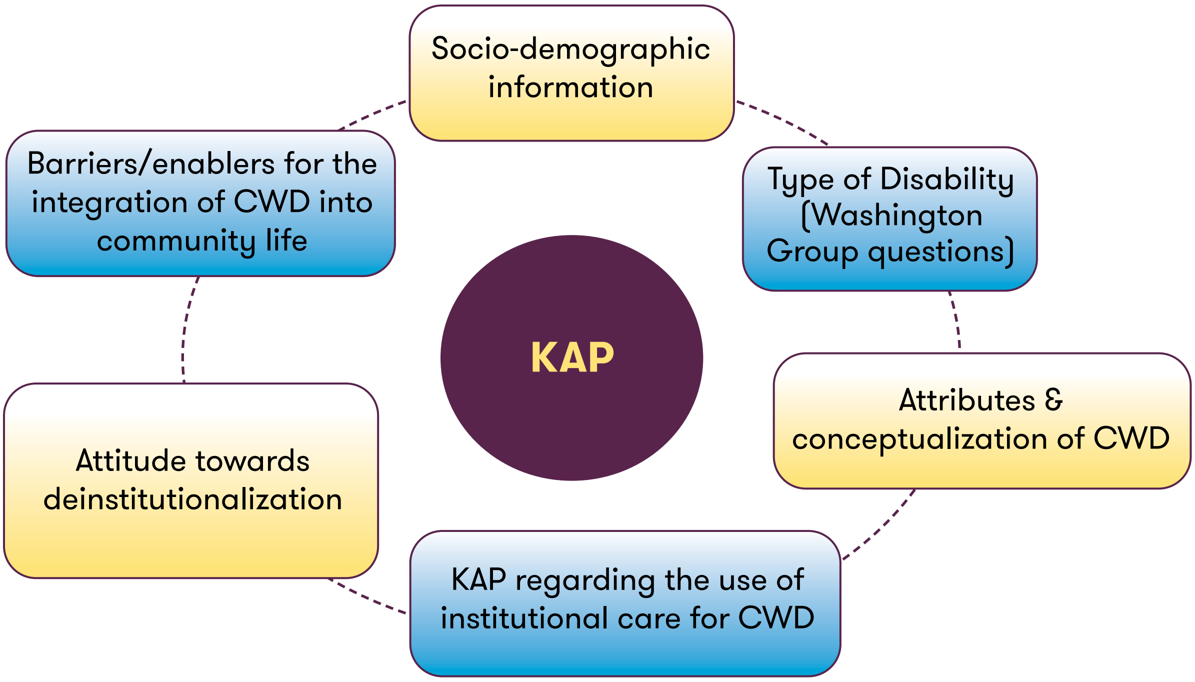

Figure 2: Conceptual framework of the KAP survey for CWD in Rwanda

2.4 Data Collection

The approved questionnaire was prepared and uploaded onto tablets using Open Data Kit software (ODK). The latter helps collect field data on a mobile device and transmit it to a server from where they are extracted for analysis. In addition, the GPS incorporated in the ODK helped to regularly monitor the geographical location and progress of the interviews.

Focus group discussions with parents were also conducted by the research team in rural and urban areas using open-ended questions, interviews, and focus group guides developed using the available literature. These triggered discussions helped to understand the attitudes and behaviours related to children with disabilities. The research team also purposively identified stakeholders working directly with children with disabilities and conducted in-depth interviews. These mainly included leaders of residential institutions for children with disabilities, local professionals such as social workers and counsellors, and leaders of associations of people living with a disability. Three focus group discussions were held. The first focus group included parents who have a child with a disability but whose child never had to stay in an institution long-term. This group recruited parents living in Gasabo District in Kigali. At the time of the study, the second group included parents whose children were staying in an institution but were in the process of being de-institutionalized. This group was organised in Kicukiro District in Kigali, but parents were recruited from different districts such as Rwamagana and Gasabo. The inclusion criterion was to have children in an institution located in Kicukiro, Kigali. The third group included parents whose children had lived in an institution in the past but were currently back in their families. This group discussion was held in Nyagatare District in the Eastern Province and included parents who used an institution located in the same district. The choice of district was based on convenience since it was the only district that could bring together parents who once had children in that institution. Table 2 provides demographic details of the participants per group.

Each group session lasted approximately between 60 and 90 minutes and was conducted in Kinyarwanda. A safe and convenient place, free from distraction and noise, was arranged at each venue to facilitate confidential discussions and free interaction among participants. An audio recording was used after permission had been sought and granted from participants.

Table 2: Participants recruited in each focus group

Focus group	Provenance	Category of participants	Female	Male	Total
Focus Group 1	Gasabo	Parents with no contact with an institution	3	2	5
Focus Group 2	Kicukiro	Parents whose children are placed in an institution	3	2	5
Focus Group 3	Nyagatare	Parents whose children have been received back home after being in an institution	5	2	7

The data collected from professionals working in the community, whose services are closely linked with residential institutions/centres for children with disabilities, considered the representativeness of the five provinces of Rwanda. Upon guidance from HHC, NCPD, NCDA and field informants, respondents were purposively sampled from local professionals and relevant stakeholders, notably the leaders of residential institutions for children, social workers, psychologists/counsellors, therapists, educators, community leaders, and others directly or indirectly involved with children with disabilities, or potentially able to generate reliable data. These were identified by residential institutions and organizations HHC works with.

Using an open-ended interview guide, respondents' views were systematically recorded and compiled to generate an analytical interpretation. The presentation of the findings, therefore, is also a thematic assemblage of field professionals' discoveries of:

- Experiences working with children with disabilities.
- The situation of children with disabilities in communities.
- Interactions of children with disabilities in their families .
- Main challenges and enablers in providing services to children with disabilities.
- Available means for children with disabilities within the community.
- Institutional care for children with disabilities.
- Recommendations for improving the lives of children with disabilities and their integration into the community.

2.5 Data Analysis

2.5.1. Quantitative data analysis

The data entry process was conducted using tablets; data cleaning was processed using STATA 16; advanced data analysis was performed using SPSS V25 software. Socio-demographic characteristics of study participants, type of disability, and their level of KAP was generated and presented using tables with absolute numbers or in percentage form, based on the type of variable.

The study team performed bivariate analysis to assess the relationship between different variables: demographic factors (relationship between gender, age, sex or income, education, family size) and KAP; urban/rural, availability of institution for children with disabilities and KAP; type of disability (physical, visual, hearing, speech, mental, intellectual, multiple) and KAP; the relationship between the conceptualization/attributes of children with disabilities and the decisions parents made about children (use of institutional care for children with disabilities, and the integration of children with disabilities into community life). Later, the analysis involved multivariate analysis with potential predictors.

2.5.2. Qualitative data analysis

Data from focus group discussions and key informant interviews were coded using NVivo software. They were analysed using familiarization (Green et al., 2014) which entailed listening to the voice recordings and reviewing the field notes to gain an immediate impression of the data. Researchers identified a thematic framework through which they developed a coding scheme based on the responses provided by participants. Charting was then done by creating an analytical framework and rearranging data according to themes. Finally, the researchers did mapping and interpreted the data to identify relationships between codes using a framework matrix.

Audio recorded data was transcribed verbatim by one of the research team members, who also translated the transcribed data. Nvivo 12 was used for data storage and coding. A deductive content analysis approach was used. The unit of analysis was a focus group transcript. First transcripts were read paragraph by paragraph to identify segments of the transcripts that fit into the four predefined categories:

1. Knowledge about disability.
2. Needs of children with a disability.
3. Attitudes/perception towards children with a disability.
4. Perceptions towards long-term institutional care and homecare for children with a disability.

These segments were condensed into codes and grouped into sub-themes based on their resemblance and occurrence. Next, similar sub-themes were linked together and were classified into themes.

2.6 Ethical Considerations

- Ethical approval: The study was subject to ethical approval by the Institutional Review Board of the College of Medicine and Health Sciences, University of Rwanda.
- Consent: Participants were asked to sign a consent form before participating in the study to comply with ethical principles,
- Only willing and available respondents were interviewed.
- Confidentiality: The study team kept participants' information confidential by using codes instead of names and a password-protected database.
- Privacy: To ensure privacy and confidentiality, all interviews were conducted in a convenient place where other people could not listen in or follow the proceedings.
- Special consideration regarding disability: The study team was comprised of specialists to ensure that children's rights, especially those with disabilities, were respected throughout the research process. The data collection team was trained on research ethics and the appropriate treatment of vulnerable study respondents and children.

3. FINDINGS

3.1 Socio-Demographic Characteristics of Participants

3.1.1 Socio-Demographic characteristics of survey respondents

The table below describes the socio-demographic information of respondents. It summarizes the number of respondents per district, residence area, gender, age group, level of education and marital status.

Table 3: Socio-Demographic characteristics of respondents

Variables	Characteristics	Frequency	Percentage
Respondent's sex	Male	218	27
	Female	589	73
Residence	Urban	284	35,2
	Rural	523	64,8
Living in sector with residential institution for children with disabilities	No	584	72,4
	Yes	223	27,6
Respondent's religion	Christian	763	94,6
	Muslim	38	4,7
	None	6	0,7
Respondent's correct age (in completed years)	≤34 years	209	25.9
	35-47 years	394	48,8
	≥48 years	204	25,3
	Mean=41,46 Max=86 Min=18 SD=10,420		
Level of education attainment	Primary	511	63,3
	Lower secondary	60	7,4
	Secondary	29	3,6
	Diploma	2	0,2
	Bachelor's degree	6	0,7
	Postgraduate degree	1	0,1
	Other training	7	0,9
	No formal education	191	23,7
Current marital status	Single	39	4,8
	Currently married	477	59,1
	Separated	57	7,7
	Divorced	30	3,7
	Widowed	76	9,4
	Cohabitation	128	15,9
Current work status	Unemployed (No paid job)	484	60
	Paid job in Public sector (government employee)	4	0,5
	Paid job in the Private sector	8	1
	Self-employed Informal employment	175	21,7
	Others	136	16,9
Average household income per month (Rwf)	Mean=14.201,12 Max=400.000 Min=0 SD = 24.808,802		
Ubudehe category of household (January 2020)	Category 1	144	17,8
	Category 2	324	40,1
	Category 3	339	42,1
Size of household	Minimum 2 Maximum 14 Mean ~6 SD ~2		

A total of 807 caregivers/parents of children with disabilities completed the questionnaire. Many of the participants were female (73%). Most of the participants (763 or 94.5%) reported they were Christian. More participants were from rural areas (64.8%) than urban areas (35.8%).

Regarding age, 48.8% of participants were aged between 35 and 47 years, 25.9% were 48 years or older, while 25.3% were 34 years or under. The mean age of participants was 41.46 years. The participant range was a minimum of 18 years and a maximum of 86 years. The majority of participants were married (59.1%), followed by cohabiting (15.9%), widowed (9.4%), separated (7.7%), single (4.8%), and divorced (3.7%).

In terms of education, the majority reported to have attended primary school (63.3%), followed by those who mentioned having a lower secondary level of education (7.4%). Meanwhile, a significant proportion (23.7%) had no formal education, and only 3.6% completed secondary school.

In terms of employment status, 60% of participants reported to be unemployed. In comparison, 21.7% said they were self-employed in informal employment or by other subsistence jobs (16.9%). The mean household income per month was 14.201,12RWF with a maximum of 400.000 RWFs and a minimum of 0 RWF. In relation to the Ubudehe category of household[1] (January 2020), which represents the socio-economic status of households on a scale of 1 (vulnerable households) to 4 (wealthy households), most participants reported that they were in category 3 (42.1%) followed by category 2 (40.1%) and category 1(17.8%).

When it comes to the size of the household, results show the mean household size to be ~6 members with a maximum of 14 persons and a minimum of 2 persons.

3.1.2 Key characteristics of informants

All 10 professionals (6 male & 4 female) who were interviewed had between 1 and 11 years of experience working with children with disabilities. However, only 5 had relevant professional training (1 B.Ed in special educational needs (SEN); 4 CPDs in SEN; 1 bachelor's degree with honours in physiotherapy, and 1 bachelor's degree with honours in psychology). The other 3 had substantial experience, had participated in short courses or obtained unrelated qualifications, including the leader of one of the residential institutions in the Southern Province who has a master's degree in public health.

The adjectives and expressions that dominated responses from professionals regarding why they joined the profession seemed quite varied and unrelated including:

- It is my career.
- I was appointed as a qualified educator with some skills in educating children with disabilities.
- I missed schooling my child and I decided to work with him and others.

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[1] Ubudehe socioeconomic category 1 is comprised of very poor, vulnerable citizens unable to feed themselves without assistance; category 2 is comprised of citizens who can afford to eat once or twice a day and afford some form of rented or lower class owned accommodation; category 3 is comprised of citizens who are employed, farmers who have moved beyond subsistence farming or owners of small and medium scale enterprises; category 4 is comprised of wealthy people (citizens with big businesses, employees who have full-time employment with organizations, industries or companies, government employees, owners of lockdown shops or markets and owners of commercial transport or trucks (Government of Rwanda 2015; MINALOC 2015).

- ‘Umuhamagaro’ (a call into the profession).
- I did an entry examination.
- I chose to work with children with disabilities as part of my professional career.
- I personally like social work, and working with vulnerable children is my passion.

Clearly, professional guidelines of who can work in residential institutions for children with disabilities are not yet nationally harmonised or formalised, especially in leadership and management positions. It is only in one institution for children with disabilities where relevantly qualified professionals testified to have been formerly recruited and employed by the Ministry of Education.

In the same way, when professionals were asked about their levels of interest, feelings, demands and professional transformations experienced when working with children with disabilities, they were equally varied. Below are some of the testimonies:

Table 4: Testimonies by professionals on their experiences and engagement with children with disabilities

Interest	Feeling	Demands	Transformations
A qualified, male SEN Coordinator (SENCO) with 2 years of experience: • Happy and proud • Need training in case management, childcare, inclusive lesson planning, delivery & SEN assessment; developing IEP, psychology, braille & sign language. • Now I know that what is needed is to create a friendly and accessible environment for children with disabilities. • What I like most is developing IEP & SEN assessments.	A trained female head of an institution and a parent of a child with disabilities with 5 years of experience: • I feel passionate • Continuous refreshment in SEN to update skills is important • Working with children with disabilities changed me and I now know more about them • I liked the way children with disabilities surprise people with their abilities, hidden behind their challenges. • Very few schools welcome children with disabilities.	Religious female, qualified as A 2 ordinary teacher with 11 years’ experience: • It is good but difficult • I feel confident to be with children with disabilities. • Skills required on how to care for children with disabilities. • To teach a children with disabilities needs love and vocation. • I like to teach Children with disabilities because they were considered as unable but I have seen that they are able.	Qualified male medical professional with 1 year experience: • One has to be patient and professional • Working with children with disabilities has changed me positively; now I know that disability is not an inability and what is needed is to remove barriers and create opportunities for them. • Their mothers are generally strong but they ask if their child is going to be like other children.

Depending on the level of attachment or engagement with children with disabilities, type of employment, training/qualifications and/or understanding of the needs of children with disabilities, professionals expressed varying levels of satisfaction towards their professional contributions made to children with disabilities. As indicated in Table 4, the feelings ranged from an emotional and charitable interpretation of the call to support children with disabilities, to one of purely professional or civil obligation. However, they all testify there to be a shortage of human and material resources, or inadequacy in provisions for children with disabilities at both institutional and/or community levels. Worryingly, no participants mentioned the need for a defined national strategy through which provisions for children with disabilities could be structured.

Interestingly, 100% of the professionals have had some form of training in their respective professions to support children with disabilities; ranging from a workshop lasting a few days, to postgraduate studies. However, they all expressed the need for more professional training to improve their knowledge & skills, because disability needs are varied and therefore require varying professional interventions. Those who have had training through government residential institutions have also benefited from government support. However, 67% were trained in-service by international agencies. Only two professionals had a bachelor's degree (B.Ed SEN) related to special needs and only two testified to being employed by the government:

- *"I trained in UR CE SISNE and received in-service training, but I still need to learn more about the care of children with disabilities as long as I keep interacting with different cases..... I feel I need more formal training so that I may be able to train others ....."* Professional from Ruhango District.
- *"Yes, I am trained but it is not enough in the field of caring for children with disabilities .... the training obtained was not enough, I still need more training.....".* Professional from Gakenke District.
- *"I am trained but not adequately, I need more skills since I meet children with different challenges which require me to have continuous professional training....* Professional from Gisagara District.
- *"Yes I wish to learn more because this domain is complicated"* Professional from Kicukiro District.

Evidently, professionals feel services in Rwandan residential institutions for children with disabilities is dissatisfactory, mainly due to inadequate skills or training of professionals involved, or because the residential institutions are unable to employ or adequately manage the training of professionals. In addition, since most of the residential institutions are private, their budget does not seem to afford adequately qualified personnel.

3.1.3 Number of children aged 2-17 and children with disabilities in the household

A total of 2,258 children aged 2-17 years old were listed in 807 households. Out of these children, 38% were reported to have some form of disability while 62% did not have a form of disability.

Key informants, during interviews, alluded to a very high prevalence of unidentified children with disabilities in communities, both in terms of number and category. They equally affirm that the majority do not receive basic service provisions, notably;

education, therapy, psychosocial services, and seem to be a burden on the family.

The Special Educational Needs Coordinator (SENCO) of Ruhango District affirmed that the number and categories of children with disabilities in schools is unknown. He observed that the number of these children not attending school seems quite high and unknown, while the few schools that accommodate some of the children are ill equipped to provide them with a proper education, due to limited human and material resources.

The head of a centre for children with disabilities in Gisagara was the only one able to estimate the prevalence of children with disabilities (at about 854), of which only approximately 15% are in school. Their progress and whether they have obtained qualifications is uncertain.

Table 5: Number of children in the household by disability

Age (years)	Have a disability				
	No		Yes		
	Frequency	Percentage	Frequency	Percentage	Total
≤7 years	476	61,3	301	38,7	**777**
8-11 years	347	58,7	245	41,3	**592**
12-17 years	574	64.6	315	35,4	**889**
Total	1397	62	861	38	**2258**

3.1.4 Parental living status and primary caregiver

Regarding their parental status, results presented in Table 6 show that for the majority of children, they have both parents alive (86.7%), while for 12.5% of children only one parent was still alive, and for 0.7% both parents have died. 33% reported the mother to be the primary caregiver who stays at home with the child with disabilities. Remarkably, the second most common primary caregiver was a sibling of the child with disabilities (23%). Fathers follow thereafter at 10.7%.

Table 6: Parental living status and primary caregiver

Characteristics	Frequency	Percentage
Both parents alive	700	86.7
One parent alive	101	12.5
Both parents died	6	0.7
Primary caregiver:		
Mother	266	33
Father	86	10.7
Grandmother	54	6.7
Grandfather	12	1.5
Older sibling	103	12.8
Younger sibling	82	10.2
Other	61	7.6

3.1.5 Area where the child with disabilities goes for learning and care, and reason for not attending school

Regarding the area where children with disabilities goes for learning and care, most of the parents surveyed said that their child with disabilities attends the local school with other local children (40%). 3.7% of parents reported that their child attends a special school for children with disabilities.

Alarmingly, more than half of parents said their child with disabilities does not go to school (54%). The most frequent reason why parents do not send their child to school is that the family cannot afford the school fees (44.2%). The second most frequently reported reason was that the school does not let the child attend because of her/his disability (37%). Some parents also reported that the family does not want the child to attend school (4.2%).

Table 7: Area where children with disabilities go for learning and care, and reason for not attending school

Area where children with disabilities goes for learning and care	A local school with other local children	323 (40%)
	Special school for children with disabilities	30 (3.7%)
	Vocational Centre	1 (0.1%)
	Other	17 (2.1%)
	The child does not go to school	436 (54%)
Reason for not attending school	The family does not want the child to attend school	22 (4.2%)
	The school does not let the child attend because of her/his disability	194 (37%)
	The family cannot afford the fees to send the child to school	232 (44.2%)
	There is no school nearby/ The nearby school is not accessible	77 (14.7%)

3.2. Type of Disability

3.2.1 Type of children's disability as reported by parents

Parents were requested to list all children living in the household and report the type of disability for children with disabilities (open question). In terms of the types of disability, results presented in Table 8 show the various forms of disability reported: physical disability (34.7%), multiple disabilities (24.2%), mental and intellectual disability (20.2%), visual disability (7.9%), speaking disability (5.2%), hearing and eyesight disability (3,6%), hearing and speaking disability (1.4%), hearing disability (1.4%), and a skin condition (1.2%) amongst others.

Table 8: Type of children's disability as reported by parents

Type of Children's Disability	Frequency	Percentage
Physical	298	34.7
Visual	68	7.9
Hearing/speaking	12	1.4
Hearing/eyesight	31	3.6
Mental/intellectual	174	20.2
Hearing	12	1.4
Multiple	208	24.2
Speaking	45	5.2
Skin	10	1.2
Others	2	0.2

3.2.2 Functional disability using Washington Group Questions

In terms of functional disability (adapted from the Washington Group short set on functioning, alternative wording for proxy respondent), the results presented in Table 9 show that most of the studied children with disabilities (91.3%) did not have any, or had minimal, difficulties with their eyesight. In comparison, 2.4% could not see at all. According to responses provided by parents, 6.7 % of children were unable to hear at all or could hear but with a lot of difficulty even when using a hearing aid (4.1%); 15% were unable to walk or climb steps at all, and 22% of children could do but with a lot of difficulty. The study revealed that 15.8% of parents reported their children with disabilities to have difficulty with self-care or were unable to bathe or dress themselves (19.4 %). 27.3% reported their children with disabilities to have many difficulties or could not remember or concentrate. 17.7% of children with disabilities could not communicate (for example, understanding others or others understanding him/her).

Table 9: Functional disability using Washington Group Questions

Functional Disability	No difficulty		Yes, some difficulty		Yes, a lot of difficulties		Cannot do it at all		Missing	Total
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**		
Difficulty seeing, even if wearing glasses	683	79.3	102	11.9	55	6.4	21	2.4	0	861
Difficulty hearing, even if using a hearing aid	655	79.4	81	9.8	34	4.1	55	6.7	36	825
Difficulty walking or climbing steps	405	47	138	16	190	22	128	15	0	861
Difficulty remembering or concentrating	451	52.4	175	20.3	157	18.2	78	9.1	0	861
Difficulty with self-care such as washing or dressing	373	43.3	185	21.5	136	15.8	167	19.4	0	861
Difficulty communicating, (for example understanding others or others understanding him/her)	414	48	135	15.7	160	18.6	152	17.7	0	861

3.3 Attitudes regarding children with disabilities

3.3.1 Attributes ascribed to children with disabilities

Parents and caregivers were requested to think about their child with disabilities; trying to visualize him or her and fill in the following statements with adjectives which came to mind, *'The child with disabilities is______.'* Having completed this task, parents were also asked to decide for each characteristic whether it was positive, negative, or neutral. The results presented in Table 10 below show that there were more negative attributes compared to positive ones. For example, 79.9% of all firstly reported attributes were later classified by parents as negative, while only 18.8% of them were positive.

Table 10: The first attribute ascribed to children with disabilities

Scale	Frequency	Valid Percent
Neutral	10	1.2
Negative	645	79.9
Positive	152	18.8

According to Illes (2019), the language around disability can offer a barometer to gauge and understand social attitudes and perspectives. The majority of first words used by parents were negative. This probably indicates what parents themselves think about their children and is a reflection of stigmatizing words and negative attributes in the surrounding community. Terms such as *"Sagihanga", "Kaguru", Marari", "Kanono", "Big head", "Nyirakanyonjo"* reflect critical perspectives of the deficit and the organ affected. Other terms focus on the consequence of the disability: *"Irobo" (half of a kilogram), igikururanda (crawling animal).* Other terms simply degrade children with disabilities to the status of a mere object *("Icyontazi"),* animal *("Gihunyira", "Icyugu")* or a strange and unclassifiable creature *"Kiburiburi""ikizeze""Kijogoro", "bihurihuri".* These terms manifest negative attitudes and stereotypes that inevitably lead to prejudice and affect children with disabilities. Other terms such as *"debile", "Ikirimarima", "ikiwerewere"* apply specifically to children with intellectual or mental disabilities while others such as *"ikimuga" (severely disabled); "Gicumba" (lame) "karema" (disabled);*

"Kajorite" (physically handicapped) are referring to the physical disability. *"Kiragi" ("deaf"),* is commonly used to refer to children with a hearing and speaking disability; "*igipfamatwi" (deaf)* for children with a hearing impairment.

In contrast, positive attributes reported by parents humanely referred to children with disabilities (he/she is first and foremost a human being; he/she is a child like everyone else), their nationality (he/she is first and foremost Rwandan), their value (he/she has a value), their innocence (he/she is an angel), their character (he/she is kind to others), their physical appearance (she is beautiful), their future and value (he/she has a bright future), etc.

Neutral attributes were mainly descriptive and portrayed the impairment (e.g. someone not able to be involved in all activities but who is able to do other things); or a characteristic without using stigmatizing words (someone who is not able to hear or speak correctly).

3.3.2 Attitudes of parents and the general community according to professionals

The attitudes of parents and the general community were underscored by 100% of interviewed key informants as largely negative towards disability, while 50% indicated that the attitude about disability was largely positive. The latter trend can be attributed to community training sessions organized and supported by international NGOs, notably Humanity & Inclusion, World Vision, APESEC GIRIMPUHWE, Duterimbere and possibly a few others. Like other key informants, the head of a centre for children with disabilities in Gisagara affirmed that the level of community understanding about disability seems to be improving due to sensitization and political orientation towards mutual respect and equal opportunities for all. All respondents insisted that more efforts are required to change negative attitudes towards children with disabilities which are often exaggerated by deprivation in most families and communities. They jointly agreed that these are major factors which contribute to inadequate support to children at home, and an inability for families to access educational and therapeutic services that are critical to the children.

Table 11: Names given to children with disabilities and their ascribed attributes

Negative		Positive	
Kinyarwanda Word	**Translation**	**Kinyarwanda Word**	**Translation**
Ntabwo’ari’umwana	Not a child	N’umuntu	Human being
Bihurihuri:	Mentally ill	Kiremwamuntu	God-created
Abasazi:	Mad	Mubona’kimwe’nabandi	Seen as an equal human
Agahwinini:	The little destabilized	Mubona’nkabandi’bana	Considered as a peer
Agakuri	The little one	Mufanta’nkabandi’bana	Considered like other children
Akajorite	The cause	Ni’umuntu’nkuwundi	Equal human
Akamuga	The little defunct one	N’umwana’nk’abandi	Same as other children
Akaragi	The little speechless one	Ninkabandi’bose	Like other people
Akarema	The little deformed one	Numugiraneza	Big-hearted
Big head	The big headed one	N’umuntu	A person
Bikondo	The droopy one	Numunyagaciro	Valued
Birorirori	The bad sighted one	Numunyamahirwe	Quite lucky
Butoki	Bad fingers	Ni’mwiza	Quite beautiful
Gicuri	The unstable one	N’umugwaneza	Big-hearted
Gihunyira	The one who brings bad luck	N’umujyambere	Part of the future
Gipfamatwi	The defunct-eared one	Umunezero’kuri’njye	My happiness
Gitamutwe	The absentminded one	umunyarwanda	Rwandan citizen
Icyugu	The lizard	Numwana’wanjye	My child
Igihwinini	The unstable one	Ni’umwana ‘nkuko’imana’yamumpaye	God’s gift
Igikuri	The little one	Nibeza’kurinjye	Quite beautiful to me
Ijisho moya	One–eyed	N’umwizerwa	Quite trustworthy
Ikibura buryo	The clumsy one	N’umumalayika	The angel
Ikidebire	The big mentally ill one	Neutral	
Ikirimarima	The big stupid one	Utumva’cyangwa’utavuga	Unable to speak or talk
Ikirindirindi	The big lousy one	Utumva’ntavuge	Unable to speak & talk
Ikitumva	The big defunct-eared one	Ubana’n’ubumuga	Lives with a disability
Intandame	The deformed one	Ubuz’urugingo	Lost a body part
Kaboko	The small-handed one	Ubuz’urugingo’cyangwa’ruhari’ ariko’rudakora	Lost a body function
Ikgoryi	The stupid one	Ufite’ingingo’zidakora’neza	Dysfunctional body parts
Kaguru	The little leg	Udashoboye’gukora’imirimo’yose	Unable to do chores
Kajanja	The little-pawed one	Utumva’cyangwa’utavuga	Unable to speak or talk
Muteragahinda	The source of sadness	Utumva’ntavuge	Unable to speak & talk
Nyamweru	The white one		
Nyirabitwi	The big-eared one		
Nyiraburema	The mother of the lame		
Nyirakaboko	The mother of the little hand		
Marari	The disfigured-eyed		
Maso	The big-eyed one		
Mitambiko	The horizontal one		
Mitunu	The glaring-eyed one		

Appendix 1 depicts in pictorial form the terms people use to describe children with disabilities in the studied communities.

3.3.3 Words used for children without disabilities

Participants were also asked to provide at least three local terms used to describe children without disabilities. After completing this task, participants were asked to decide for each term whether it was positive, negative, or neutral. The results presented in Table 12 indicate there were more positive attributes than negative ones. For example, 90.7% of all first reported attributes were extremely positive while only 6.9% were negative.

Table 12: The first attribute ascribed to children without disabilities

Scale	Frequency	Valid Percent
Neutral	19	2.4
Negative	56	6.9
Positive	732	90.7

3.3.4 Feelings frequently experienced by parents about their child with disabilities

The researchers also explored how parents and caregivers felt (affective attitude) towards children with disabilities. They were requested to list three relevant emotions (feelings that they experience when they see, meet, or think about their child with disabilities). Having completed this task, they were asked to decide whether each feeling was positive, negative, or neutral. The results presented in Table 13 show there were more negative feelings than positive ones. For example, 72.6% of all the reported feelings were extremely negative while only 22.8% were positive.

Table 13: First feeling (affective attitude) towards children with disabilities

Scale	Frequency	Valid Percent
Neutral	37	4.6
Negative	586	72.6
Positive	184	22.8

The researchers also asked participants to provide at least three relevant emotions and feelings that they experience when they see, meet or think about a child without a disability. Participants also decided for each feeling whether it was positive, negative, or neutral. The results presented in Table 14 show there were more positive feelings than negative ones.

Table 14: First feeling towards children without disabilities

Scale	Frequency	Percent
Neutral	12	1.5
Negative	47	5.8
Positive	748	92.7

3.3.5 Feelings frequently experienced by parents about children with disabilities

All participants were asked to list three dominant emotions about their children with disabilities. Some participants found it difficult to report three different feelings so reported only one or two and left the third-row empty. Results presented in Table 15 show a range of emotions felt by parents when they see, meet or think about children with disabilities.

Table 15: Feelings frequently experienced by parents about children with disabilities

	Local language	Meaning	Frequency
Negative feelings	Kugira intimba, agahinda gakabije, Kumva wihebye, ushaka kwiyahura	Feeling of sadness and depression	673
	Kumva impinduka mu mubiri	Somatic or physical sensation	22
	Kumva ufite umujinya, wamutonganya wamukubita	Feelings of anger, furious against children with disabilities/God/Father, losing control	104
	Kumva uhangayitse, ufite ubwoba	Feeling anxious	79
	Kugira ipfunwe	Feeling of shame	41
	Kumva ukometse, uhungabanye	Feeling of being broken/traumatized	68
	Kumva utabasha kwakira	Unacceptable situation, Unbearable pain (I don't feel like a parent, I would like to move from home)	31
Positive feelings	Kugira impuhwe, Igishyika, Imbabazi	Compassion/empathy	332
	Nariyakiriye, numva namwitaho, namufata neza	Acceptance, love, positive consideration, care, willingness (wish to provide the maximum possible care)	218
	Ndamukunda birenze, Umugisha wanjye	Joy, pride and happiness	44
	Azakira	Hope that he/she will be completely cured (sort of denial but considered by parents as positive)	16
Neutral	Ntibinshimishije ariko ntibinambabaje cyane	No specific feelings, not sad or happy	70

Appendix 2 shows examples of feelings frequently experienced by parents about children with disabilities.

Table 16: Other feelings experienced by parents about children with disabilities

Sadness & Depression		**Physical sensation**	
Nakwiyahura	I feel suicidal	Bituma'umutim'utera	Makes my heart throb
Ndadwara	I feel sickly	Guhind'umushyitsi	Shivering
Ndarira	I cry	Gutsikira'mumutima	Heart misses a beat
Nariragusa	I only cry	Intimba'kumutima	Heavy hearted
Agahinda'karanyica	I feel sad	Ndasuhererwa	Goes cold
Agahinda'kenshi	I feel too sad	Ndikanga	I get shocked
akababaro	I feel bad	Nshika'intege	I lose courage
intimba	heartbroken	Numv'umutim'unsimbutse	My heart jumps
Ishavu	sadness	Numva'ntatuje	I am always restless
Umwijima'mumutima	I feel darkness in my heart	Birandenga	Too much for me
Ntan'ibyishimo'ngira	I am never happy	Gusesu'urumeza	Develops goose bumps
Umubabar'ukabije	I feel too much pain	Gusharirirwa	Bitterness
Nshenguk'umutima	My heart breaks	Gushenguk'umutima	Feels heartbroken
Ikiniga	Anger	Mpagarits'umutima	Always worried
Kwiheba	Loss of hope	**Anger & losing control**	
Gutekereza'nabi	Bad feelings	Mpita'ntongana Ndaserera'ngatongana	Breaks into fights
ndigunga	Loneliness	Umujinya, Uburakari	Anger
Numvantar'umuntu	I feel non-human	Uburakari'burenze	Too much anger
Mporan'agahinda	Always sad	Mbanumva'narwana	Feels like fighting
Agahinda'gakabije	Too much sadness	Nkijima	Go black-hearted
Nkomerek'umutima	Heartbroken	Kamer'irabaduka	Natural feelings
Nibaz'icyatumye'mbaho	Should not have lived	Natay'umutwe	Lose my head
Fear & anxiety		Kuk'imana yabaremany' ubumuga	Questioning God for creating disability
Ubwoba	Fear		

Kumutima haz’ubwoba	I feel fear in my heart
Mba mfite nk’ubwoba	I feel too much fear
Impungenge	Anxious
Azigezakuki?	What will s/he do
Kwikanga	Shock
Mbanumva mpangayitse	I feel worried
Mporana’impungenge	I am always anxious
Mwibazaho ejo hazaza	I am worried of his/her future
Mporana’ umuhangayiko’ udashira	Azakira
Shame	
Ipfunwe	I feel ashamed
Ipfunwe’mu’bandi	I feel ashamed when with other parents
Ntisanzuye’ mu bandi’ babyeyi	I never feel at ease/relaxed with others
Wumva’ utamugaragaza	I feel the need to hide him
Igisebo	He/she is shames me
Joy, Happiness & Pride	
Umugisha’iwanjye	Godly blessings
Urukundo	Love
Ishema	Pride
Kumukunda’ birenze	Too much love
Ndishima	Happy
Nezerewe	Joyful
Ndamukunda’ peeee	Loves very much
Urugwiro	Gratified
Kumufata’ neza’ kurusha’ abazima	Loves her/him more
Muha’ agaciro	Values her/him more
Numva’ namworohereza’ muri’ service’ zose	Allows her/him preferential treatments
Mbona’ namufata’ neza	Treats her/him well
Kumuba hafi	Keeps close to her/him
Kumufasha	Gives her/him support
Muha’ agaciro	Values her/him more
Kumufasha	Gives her/him support
Kumuhumuriza	Encourages her/him
Kumukunda	Loves her/him
Kumwitaho‘ cyane	Gives her/him all the support
Namwigisha	Educates her/him
Kumukuyakuya	Cuddles her/him
Kumurengera	Protects her/him
Kumusengera	Prays for her/him
Kumutega’amatwi	Listens to her/him
Kumuba’hafi’nk’ umubyeyi	Gives her/him parental care

Trauma	
Mporana’ihungabana	Always traumatized
Birampungabanya	It traumatizes me
Guhungabana	Traumatized
Guhungabana’mu’ mutima	My heart is shaken
Birankomeretsa	It hurts me
Numva’mvunitse	It breaks me
Hope	
Azakira	He will get cured
Mba’ numva’ nfite’ ikizere Mfite’ ibyiringiro’ ko’ azakira	I have hopes for better, I really think he will be cured
Kubera’ iki’ Imana’ itankiriza’ umwana’ se?	Why can’t I believe that God might cure my child? he/she will be cured
Mwifuriza’ gukira’ akaba’ muzima’ agashingirwa	I wish that s/he gets cured and normal as others and gets married
Difficulty finding acceptance & challenges	
Numwa’ntarabyaye Birutwa’ nukuba’ ntaramubyaye	I feel I am not a parent I feel like someone who never gave birth
Naramupfushije	I lost him/her, he/she is dead to me
Mbere’numvaga’nzabata	I had thought I would throw him/her away or leave the household
Ntekereza’kwimuka	I had thought I would run away
Kwinuba	Disgruntled
Aranvuna	It is costly
Birabangama Birantonda	It is challenging
Mba’mfite’ingingimira	I have my doubts
Mba’numva’angora Mbangamiwe	S/he is challenging
Binteye’ ikibazo’mu buzima’ bwange Ateza’ibibazo	Brings issues into my life
Numva’mbyijujutira	I keep complaining
Umutwaro ’kumuryango Mbanumva’aruwo’kundushya Bimbereye’umutwaro	Family burden
Ikigeragezo’kumuryango Mba’numv’arikigeragezo	Family trials
Ntagaciro’wumva’umuhaye	Do not value him/her
Kuvuga’ngo’mana’wampoy’iki?	Blame God
Nyine’ibyaye’ikiboze’irakirigata	A parent’s love is unconditional
Mpora’ numva’ naraherekeje’ ababyaye	I feel other parents are better than me
Nibaza’icyatumye’mbaho Nibaza’icy’imana’yampoye	I question why I am alive
Compassion	
Ubwuzu Impuhwe Imbabazi	Sympathy
Igishyiika	Heartfelt
Impuhwe	Kindness
Arababara	Feels hurt
Arababaje	Feels sorry
Arahungabana	Is traumatized
Arambaza	Makes me feel sorry
Namufasha	Needs help
Numugwaneza	Is kind-hearted
Numunyantegenke	Is weak
Numva’mugiriye’impuhwe’cyane	I fell sympathy for him/her
Antera’kumukunda	Makes me love him/her

3.3.6 Thoughts, beliefs and general perceptions towards children with disabilities

Thoughts, beliefs and general perceptions about a child's ability to be fully integrated into society are pre-requisites to inclusive practice in a family and community. In this study, participants were presented with a range of statements that describe disability, ability and expectations towards children with disabilities and they were asked to estimate their level of agreement with each perception or belief.

Table 17: Thoughts and beliefs towards children with disabilities

Perception	Always (%)	Sometimes (%)	Rare (%)	Never (%)	Total (%)
I think children with disabilities can grow up like everyone else and continue their way of life	347 (43%)	427 (52.9%)	20 (2.5%)	13 (1.6%)	807
I think I see no difference between children with disabilities and other children, because I see them all as children.	367 (45.5%)	378 (46.8%)	42 (5.2%)	20 (2.5%)	807
I think my child with disabilities is a beautiful and interesting child	542 (67.2%)	236 (29.2%)	17 (2.1%)	12 (1.5%)	807
I think my child with disabilities looks just as good as everyone else	563 (69.8%)	223 (27.6%)	14 (1.7%)	7 (0.9%)	807
I think and feel that children with disabilities are children who demand constant attention (a burden for caregivers)	588 (72.9%)	205 (25.4%)	11 (1.4%)	3 (0.4%)	807
I think there is nothing we can expect from children with disabilities, they are not as productive as typical children	170 (21.1%)	417 (51.7%)	114 (14.1%)	106 (13.1%)	807
When I think of children with disabilities, I feel threatened and overwhelmed	156 (19.3%)	425 (52.7%)	156 (19.3%)	70 (8.7%)	807

43% of participants agree that children with disabilities can grow up like everyone else and continue their way of life (it is possible that here participants were thinking about physical growth - "Gukura" in Kinyarwanda); 45.5% of participants perceive no difference between children with disabilities and other children because they see them all as children, and 67.2% of participants consider children with disabilities as beautiful and interesting. However, 72.9% of participants consider children with disabilities as children who demand constant attention and constitute a burden for caregivers. About 52.7% of participants feel threatened and overwhelmed when they think about children with disabilities. Similarly, 51.7% agree that there is nothing we can expect from children with disabilities as they are not as productive as children without disabilities. We can note here that there are possible differences between what people feel and what they think. The majority reported predominantly negative feelings while thoughts and beliefs tended to be positive.

3.3.7 Meaning of attributes assigned to children with disabilities

Qualitative data analysis revealed common attributes assigned to children with disabilities that complements the quantitative survey. These were grouped into three categories of negative attributes; those that stigmatize the child, those that dehumanize the child, and those that demonize the child with a disability.

Stigmatizing attributes

Names given to children with disabilities were mainly stigmatizing, referring to them based on the type of their disabilities. The most common included: ‘ikimuga’, ‘ikimara, ‘ibigoryi’, ‘debiles’, “*A child who does not hear is named ‘igipfamatwi’, one who does not speak is named ‘ikiragi’, one who does not see is named ‘impumyi’, one who does not walk is named ‘ikirema’” (FGD3, Father).*

Stigmatizing attributes were found to extend beyond the child with disability but to also be associated with the entire family of the child. Parents shared their experiences: “*My daughter has a problem of drooling. She has been named “Bikonda”, and I am named “Mama Bikonda”, our household is known as “kwa Bikonda”” (FGD1, Mother).* “*He is called the “foolish man”, “igisazi”. When I walk around, I am referred to as the mother of the “foolish man”. When I take him for a walk, as recommended by the doctors, they point at us as and say, “look at this woman, she is as foolish as her foolish son”” (FGD3, Mother).*

While the majority of participants attribute these negatives attributes to community members outside their household, one participant shared how these were also perpetuated by the father of her child. She narrated: “*My husband keeps telling me that this “kigoryi” is not his offspring because he does not give life to “ibimara”” (FGD3, Mother).*

These stigmatizing attributes were always accompanied by discrimination among community members towards children with disabilities. One mother shared how her child was sexually abused, and she did not receive justice because people did not believe her “*When she was abused and I was consulting authorities for justice, everyone dismissed me saying “why would anyone abuse “umuntu utuzuye”? Instead of abusing a normal child, they abused “kiriya”” (FGD3, Mother).*

In addition to community members and authorities, discriminatory practices were also perpetuated by healthcare professionals. One mother shared “*I was recently in R. hospital, and I went to the hospital canteen. While I was busy mashing her meal to soften it, someone in a healthcare uniform came and commented loudly: nkaba mubinjiza mute muri kantine ko ari abo kudutera isesemi! Muzabashakire kantine yabo”, saying “why do you even allow such disgusting people in the canteen? There should be a separate canteen for people like these”” (FG3, Mother).*

Dehumanizing attributes

These attributes refer to children with disabilities not as ‘humans”, but rather as “things”. These included attributes such as “*ibirambu*”, “*ruriya runtu*”, “*ibintu utamenya iyo byavuye*”, “*ikintu cy’ikiwerewere*”. These dehumanizing attributes went far and impacted the formal naming of children by parents. One mother shared how her daughter’s surname was based on her disability. She shared “*my daughter was named “N……”, a Kinyarwanda name that means ‘No worth, she is worth nothing, she is better dead’” (FGD3, Mother)*. Another mother shared how people point at her daughter as a thing, an object; *“Murebe ruriya runtu we, ngo ni urugoryi, ngo ni ururema, ngoburiya se rurya rute, runywagute?” “Look at this thing, it is debile, how does it eat or drink?” (FGD3, Mother).*

Considering children as a lesser human resulted in negative beliefs. Parents shared how they received different advice to kill their child because it was considered better if they were dead: “*A friend of mine advised me to kill her through suffocation, stating that she is better off dead anyway” (FGD2, Mother)*. Denying care to a child with a disability was also identified as another practice associated with considering them as a lesser human. A parent shared how her daughter was made to starve to death: *"I felt tired of raising her and brought her to her father. He also took her to his mother. The grandmother kept her outside saying "I am not the one who told them to give birth to this animal-like thing", later she put her in an abandoned house and refused to feed her, expecting that she will die from hunger "ngo nabura icyo arya ananywa arapfa"" (FGD3, Mother).*

Demonizing attributes

These are the attributes that referred to children with a disability as fruits of supernatural, demonic powers. Children are referred to as "*ibimanuka" (coming from the universe), "amadayimoni (demons-devils)", "abazimu" (ancestors reincarnated).* Most families believed that giving birth to a child with a disability was likely linked to sins committed by parents: "*They believe that parents of children with a disability "bagiye ikuzimu", or they performed evil rites which resulted in giving birth to children like these" (FGD1, Mother).* Others attributed the child's disability to being inherited from ancestors: *"They also say that a child's disability is inherited by family ancestors "abazimu baturuka mu miryango na karanda"" (FGD3, Father).*

3.3.8 Acceptance

Despite the sadness, burden and challenges associated with being parents to a child with a disability, participants also shared the acceptance and learning to accommodate their child's special needs. It took time for parents to learn to accept their child as the following father shared: "*It was hard at first, but now, when I look at him, I don't see disability at first. I don't even see it at all" (FGD1, Father).*

Similarly, parents also emphasized the strong parent-child bond that carries them throughout difficulties associated with having a child with a disability: "*This child is my blood, with or without a disability. I am the one who held her in my arms when she was born. I have learnt to love her as much as I love others" (FGD3, Mother).*

For other parents, it was their faith that provided them with a perspective to accept their children: "*Our children are not problems, they are solutions. They are blessings. I tell myself that if I was blessed to carry her in my womb for 9 months, to deliver her safely, while others have not been as blessed, she is a blessing to me, and that's how I should raise her" (FGD2, Mother).*

In the process of acceptance, parents have learnt different strategies to accommodate the special needs of their children and to care for them. The following narratives express their experiences: "*Before, it was hard for me to communicate with her. But now, whenever she is sad and crying, since she cannot hear what I say, I cuddle her, wipe the tears on her face, in a way to show her that I share her sadness and I am with her, she is not alone" (FGD1, Mother). "My child does not talk, does not walk; she does not even have the capacity to understand things. But when I sing for her, I call her names like "umutoniwanjye" "my favourite", "mukobwamwiza" "my beautiful girl', I cuddle her, her face brightens and she is so happy" (FGD3, Mother).*

Acceptance also included deliberate efforts to never exclude the child with a disability from activities that include other children. One mother shared: "*I said to myself that she will be treated the same as others. I have to ensure that she is kept clean, if I go shopping for clothes, she is included, I don't say I don't have much, let me just buy clothes for those that walk and go different places. No, she gets the same. I take her to ceremonies, I take her to church, she needs the same care as others" (FGD1, Mother).*

Children attending regular schools experience discriminatory practices as shared by one parent: "*I enrolled her in a regular school, but she got bullied by other children because of her disability, she was* *always coming home in tears and all her belongings were stolen. We couldn't bear it any longer and she stopped" (FGD1, Mother).*

In addition, a lack of capacity to afford the basics for daily living such as a meal, a decent place to stay, and hygiene and mobility needs were identified as challenges parents and their child with disabilities face. One parent commented *"We could go three days without a meal" (FGD2, Mother).* Coupled with the above, participants identified a constant need for proper hygiene for their child with disabilities. "*Most children with a disability like mine are not able to fulfil their needs on their own. They have to wear diapers like little children so as to keep them clean. We cannot afford these. This prevents children from being involved in social activities such as taking them to church. And to a parent, this is one source of sadness" (FGD1, Mother).*

3.3.9 Consequences of negative attitudes

The focus group discussions explored what it meant for parents to have a child with a disability. Parents described giving birth and rearing a child with a disability as parenthood riddled with challenges, characterized by a mixture of feelings such as sadness, being burdened, and accepting the need to constantly learn to accommodate the child's needs. Sadness was described as a result of the unexpected, and a lost dream. Particularly, parents expressed more sadness if the disability affected their first-born child. "*Giving birth to a child with a disability is the worst, saddest thing that happened to me, and to many other parents. If one had a choice, we would all wish to have a normal child. Up to now, it still makes me so sad. Particularly, when the child is your firstborn like mine" (FGD2, Father).* Sadness also came from comparing the child with a disability to other children and the uncertainty about the child's future. *"You feel so sad when you compare your child with the child of the neighbour. You ask yourself why my child? Other kids are in year 5, mine would be in year 5 too if he were normal. Will he ever make it? What will happen to him in the future?" (FGD1, Mother).* Such comparisons also happened when comparing siblings. This increased the feeling of sadness expressed by parents: "*I always tend to compare my child with a disability with his siblings. He is the firstborn, but his younger siblings know a lot more than him. That makes you very sad as a parent" (FGD1, Father).*

In addition to the parents' discomfort related to giving birth to a child with a disability, raising these children was also characterised by parents as a burden. Parents were clear in their accounts that the child is not a burden, but the disability is: "*The disability of a child is a burden to parents. The everyday care required leaves the parents in poverty because you cannot do anything else. You are divided between taking care of the child and looking after your family. It is a burden" (FGD1, Mother).* One parent referred to having a child with a disability as a constant "cross" that one had to carry: "*A child with disability is like a cross "umusaraba". I mean a cross because a cross is something hard to bear. It is hard to raise and to care for a child with disability. It is your own cross, and no one else's. No one will help you carry it; it is your own" (FGD2, Father).*

The other burdensome aspect associated with having a child with a disability was that of becoming a source of family conflict. The majority of parents across the groups shared that their families struggled to stay together due to their child's disability, and most ended up separating. In two of the cases, the mothers decided to leave the child with their fathers, while in three cases, it was the fathers who left the households. This also added to the burden of raising a child as a single parent. The following quotes illustrate their experiences:

"Because of the disability, her father left me. It was hard for me to raise her alone. When I came back to my family, they also made it clear that they cannot take me with her. I could not make it through" (FGD3, Mother).

"What was hard for me was when he turned 9 months, his mother left me with him, stating she couldn't bear the burden. I tried all my best to raise him, but it was challenging. My mother was still able to support me, but it eventually became harder and I had to take him to his aunt, which also became challenging until I got a place in the centre" (FGD2, Father).

Parents further emphasized that raising a child with a disability is stressful and challenging. Not knowing how to do things correctly and worrying too much for the child were reported by parents: "*It breaks your heart as a parent when your child is crying and you cannot talk to her to console her because she cannot hear you" (FGD1, Mother)*. "*Your heart is always racing when you have a child with a disability. You think for him, you worry about his inability to defend himself. Like mine does not talk and does not hear. I can't help but constantly think what if he got lost? He won't even be able to say his name" (FGD1, Father).*

Being a parent to a child with a disability made some parents take decisions that they would never have taken under different circumstances. One mother shared how it was tough deciding to drop her child outside a centre, unattended. Emotionally, she shared: "*I was so tired, I had tried all the possible help in vain, my family had advised me to kill her... the sisters in the centre for children with disabilities had refused to take her for many consecutive times. I took the toughest decision a parent could take, I took her, dropped her outside the centre, and left her there (crying)" (FGD2, Mother)*. Similarly, mothers also shared how in desperation they took decisions that they would never have had to have taken if their child did not have a disability: "*I had left my husband because of conflict. But when my child was reintegrated after years in the institution, I took all the courage I had and returned to my home to be with her. It did not mean the conflict was resolved, it meant I had to be there for her no matter what" (FGD3, Mother)*. "*I took her off my back "ndamwijishura", dropped her down and left her with her father. I was so tired. Five years of raising her alone. I spent two weeks wondering what happened to her, and they were the worst two weeks of my life. My heart was not at peace not knowing what happened to her. I went to the police station, reported myself and begged to know where my child was (crying)" (FGD3, Mother).*

3.4 Knowledge about Children with Disabilities

3.4.1 Awareness about the rights of, and services for, children with disabilities

Participants were asked whether they were aware of the rights of, and services for, children with disabilities in their community. In terms of awareness of rights, 88.7% mentioned that they were aware of a child's right to the same opportunities as everybody else, 93.3% were aware of their right to go to school, 93.7% were aware of their right to the best possible health, and 96.2% were aware of their right to not be hurt or mistreated by anybody. About 63.2% of participants did not know any legislation that seeks to protect or extend support services to children with disabilities.

Table 18: Knowledge regarding rights of children with disabilities

Knowledge	I don't know at all	I heard it a little bit	Moderately Known	Known	I know very well
Being aware of any legislation or policies relating to child protection for children with disabilities	445 (55.1%)	65 (8.1%)	119 (14.7%)	168 (20.8%)	10 (1.2%)
Being aware of children with disabilities' right to the same opportunities as everybody else	68 (8.4%)	23 (2.9%)	42 (5.2%)	555 (68.8%)	119 (14.7%)
Being aware of children with disabilities' right to go to school	37 (4.6%)	17 (2.1%)	26 (3.2%)	587 (72.7%)	140 (17.3%)
Being aware of children with disabilities' right to the best possible health	31 (3.8%)	20 (2.5%)	40 (5%)	573 (71%)	143 (17.7%)
Being aware of children with disabilities' right to not be hurt or mistreated by anybody	26 (3.2%)	5 (0.6%)	22 (2.7%)	594 (73.6%)	160 (19.8%)
Being aware of any referral systems that assist children with disabilities and their families	533 (66%)	126 (15.6%)	53 (6.6%)	94 (11.6%)	1 (0.1%)
Being aware of any religious institutions or services that assist children with disabilities and their families	620 (76.8%)	93 (11.5%)	32 (4%)	62 (7.7%)	0 (0%)

Regarding services for children with disabilities, about 25.4% of participants were aware of a residential care institution for children with disabilities as a possible placement/service for them while 41.1% knew or had heard a little bit about the specific support provided to children with disabilities raised in residential institutions. Only 3.1% of participants were aware of services for children with disabilities within their community and only 6.3% were aware of services for children with disabilities at national level. When asked if they were aware of any local groups or organizations that extend support to children with disabilities and their families, 85.5% of participants did not know of any. Only 2.4% of the participants were aware of any social protection services that assist children with disabilities and their families, while 39.1% were aware or had heard a little bit about health services available. In addition, 73.9% of participants were not aware of any education services that assist children with disabilities and their families and 66% were not aware of any referral systems.

Table 19: Knowledge about services for children with disabilities

Knowledge	I don't know at all	I heard it a little bit	Moderately Known	Known	I know very well
Being aware of any residential institution for children with disabilities as a possible placement for children with disabilities	325 (40.3%)	218 (27%)	67 (8.3%)	195 (24.2%)	2 (0.2%)
Being aware of any support for children with disabilities raised in institutions	475 (58.9%)	174 (21.6%)	62 (7.7%)	95 (11.8%)	1 (0.1%)
Being aware of any services for children with disabilities in your community	648 (80.3%)	77 (9.5%)	57 (7.1%)	25 (3.1%)	0 (0%)
Being aware of any services for children with disabilities at national level	561 (69.5%)	152 (18.8%)	43 (5.3%)	51 (6.3%)	0 (0%)
Being aware of any local groups or organizations that assist children with disabilities and their families	666 (82.5%)	79 (9.8%)	35 (4.3%)	27 (3.3%)	0 (0%)
Being aware of any health services that assist children with disabilities and their families	517 (64.1%)	110 (13.6%)	118 (14.6%)	62 (7.7%)	0 (0%)
Being aware of any education services that assist children with disabilities and their families	596 (73.9%)	102 (12.6%)	69 (8.6%)	40 (5%)	0 (0%)
Being aware of any social protection services that assist children with disabilities and their families	633 (78.4%)	98 (12.1%)	57 (7.1%)	19 (2.4%)	0 (0%)

3.4.2 Sources of information about the rights of, and services for, children with disabilities

Respondents were asked to mention the main sources of information about the rights of, and services for, children with disabilities. Results show that radio was most frequently used as the main source of information (62.7%), followed by neighbours (61.7%), friends (52.8%), family (38.5%), government officials (20.7%), television (12.1%), and newspapers (6.2%) among others.

In terms of the source of knowledge about disability and how parents came to know about the disability of their child, the majority of participants mentioned personal knowledge as the most common way through which they became aware of their child's problems. Others confirmed their initial worries through medical visits. Observing other children's achievements of certain developmental milestones or already knowing which milestone a child normally achieves at a certain age, but which was missing in their child's growth, was one source of knowledge for the majority of parents. *"In the normal life as parents; we have been seeing other parents raising their babies. At a certain age, let's say at 6 months, a child starts crawling. When mine reached that age, she could not do it like other children her age. That is when I knew something was not right" (FG1, Mother).*

"How I knew it, I had taken my daughter for a 9-month immunization. And other children her age were crawling, and when their mothers called them, they would turn toward their mothers. When I did with mine, she did not respond. Once home, I went to her back and made all possible noises, but she would not turn toward me. That is when I knew she could not hear" (FG1, Mother).

In addition to common sense, other parents learnt of the disability of their child through medical sources. Generally, this was to confirm any doubts about the child's health condition. *"I consulted different doctors, CHUK, Kibagaba, Ndera. They put him through different exams, and they are the ones who informed me that because he was born prematurely and spent a lot of weeks in an incubator, his nerves did not grow properly, and he cannot control his saliva (FG1, Mother)".*

Table 20: Source of information

Source of information	Frequency	Percentage
Family	311	38.5
Friends	426	52.8
Neighbours	498	61.7
Government Officials	167	20.7
Television	98	12.1
Radio	506	62.7
Newspapers	50	6.2
Others	97	12

3.4.3 Knowledge about the cause of disabilities

Qualitative data analysis from focus groups revealed the perceptions of parents/caregivers about disability, through their responses to questions about their understanding of parents regarding disability, needs of children with a disability, and source of information. Generally, participants demonstrated a fair understanding of their child's disability. They attributed the disability either to complications that their child had following a difficult childbirth, or to a medical illness that the child suffered from. Two sub-themes were identified. The majority of parents reported birth circumstances as the cause of their child's disability, as reported in the quotes below: *"I had a difficult childbirth, and my child was born tired. This resulted in her having multiple disabilities" (FG3 Mother Participant).* Similarly, another parent echoed: *"My son did not cry immediately when he was born. He spent two weeks in a coma. After 6 months, we noticed that he could not sit, and he started fainting. That is when we started taking him for medical consultations" (FG2 Father Participant).*

Other participants also attributed their child's disability to medical reasons. The following participant who is caring for her sister with a disability explained: *"As for me, my sister was born normal. When she was 2 years old, she got sick. She spent 3 years in a coma and when she came back to her senses, she had developed a physical and mental disability" (FG2 adoptive Mother).* It is important to note that this participant was an older sibling taking care of her sister who lives with a disability. The mother passed away and the father is not involved so she therefore found herself in the position of being a parent/caregiver for her siblings. While almost all participants demonstrated a good understanding of causes of disability, one of the participants believed that disability was inherited and transmitted from a parent to the child. She argued: *"If a father or a mother comes from a family that had been giving birth to children with a disability, your child will also have it" (FG1, Mother).*

3.5 Practices of Children with Disabilities

3.5.1 Participation of children with disabilities in family and community activities

Participants were asked for information concerning practices for children with disabilities living in the community. The results summarized in Table 21 show that more than half of the participants reported their children with disabilities to participate in household activities (53.2%), while

46.8% of them do not permit their child with disabilities to participate. The involvement of children with disabilities in domestic chores (cooking, washing clothes, and gardening) adapted to the age and type of disability provides an excellent opportunity for forming relationships with other family members and for developing useful skills for personal development. Most participants reported however that their child with disabilities does not participate in work outside the household (94.4%).

65.8% of participants reported that their child with disabilities plays with other children within the family. More than half of the participants reported that their child with disabilities attends family events such as a wedding (50.3%), and 61.3% reported that their child attends religious services with others. These results suggest that some families and communities in Rwanda have already some remarkable practices that support the integration of children with disabilities.

Table 21: Participation of children with disabilities in family and community life

Participation of children with disabilities in household activities	yes	429 (53.2%)
	no	378 (46.8%)
Type of activity	collecting firewood	90 (11.2%)
	fetching water	270(33.5%)
	gardening	19 (2.4%)
	washing clothes	204 (25.3%)
	cooking	139 (17.2%)
	other	184 (22.8%)
Participation of children with disabilities in work outside the household	yes	45(5.6%)
	no	762 (94.4%)
Type of work	farm works	3 (0.4%)
	selling services	1 (0.1%)
	making handicrafts	7 (0.9%)
	begging	1 (0.1%)
	other	35 (4.3%)
Children with disabilities play with other children within the family	Yes	531 (65.8%)
	No	276 (34.2%)
Children with disabilities attend family events such as weddings	Yes	406 (50.3%)
	No	401 (49.7%)
Children with disabilities attend religious services with others	Yes	495 (61.3%)
	No	312 (38.7%)

3.6 Attitudes towards Residential Institutions for Children with Disabilities

3.6.1 Perceived appropriateness of institutional care for children with disabilities

In terms of the appropriateness of institutional care for children with disabilities, results indicated the commonly held misconception, that residential institutions are acceptable and appropriate for children with disabilities, is still prevalent among surveyed parents. 74.7% of participants still think that raising children in residential institutions is normal and appropriate. Also, 67% of participants agreed that children with disabilities have never (formerly) been neglected in residential institutions where they sleep, so there is no reason why they should be brought home. Moreover, 65.7% of participants think that children with disabilities cannot live at home, without having to be constantly cared for. 57.6% of participants agreed that ending the care of children in residential institutions where they sleep will increase the severity of a child's functional limitations.

The view among professionals (key informants) as to the appropriateness of institutional care for children with disabilities was quite as varied as the respondents' backgrounds and perceptions. There seem to be as many (50%) key informants who approve of the institutionalization of children with disabilities as those who support the care of children with disabilities in families (50%).

Table 22: Perceived appropriateness of institutional care for children with disabilities

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
For me it is normal and appropriate to raise children in residential institutions	10 (1.2%)	135 (16.7%)	59 (7.3%)	367 (45.5%)	236 (29.2%)
Children with disabilities have never (formerly) been neglected in the institutions where they sleep, I don't see why they should be brought back home	10 (1.2%)	157 (19.5%)	99 (12.3%)	342 (42.4%)	199 (24.7%)
I don't think children with disabilities can live at home without having to be constantly cared for	55 (6.8%)	155 (19.2%)	67 (8.3%)	342 (42.4%)	188 (23.3%)
Stopping the care of children in institutions where they sleep will increase the risk and severity of their functional limitations	60 (7.4%)	201 (24.9%)	81 (10%)	285 (35.3%)	180 (22.3%)

3.6.2 Attitudes towards the deinstitutionalization of children with disabilities

Overall, most participants hold a favourable attitude towards the deinstitutionalization of care for children with disabilities. Results in Table 23 show that 12.3%, 46% and 24.3% of participants strongly agree, agree or slightly agree respectively to the assertion that *"I believe we should transition from institutional care to family and community-based alternatives*". Similarly, participants strongly agree (18.5%), agree (52.5%) or slightly agree (19.5%) to the assertion that *"I would consider raising my children with disabilities in the family"*. Participants were aware of the advantages of removing children with disabilities from residential institutional care to raise them into families and mentioned the disadvantages of raising children in residential institutions.

In addition, the experiences of parents who have received children back home were explored during the focus group discussion. This was relevant to participants in group 3. Overall, parents described deinstitutionalisation as a difficult transition, but which benefitted their children and their own lives as parents. Even though parents had been prepared for the transition, they described the transition as difficult to handle at first, as one parent shared: *"It took a long time to get used to the idea of having the children back in our home" (FGD3, Father).*

Even when parents finally came to terms with the idea, other family members made the transition more difficult:

"Then came the time when all children had to be returned to their families. We got prepared and we understood it. I informed my family, but they were very sceptical: how will you be able to work? How will the other children continue going to school?…. Then when the child was finally home, it is like a war was declared. Three days at home, they started complaining of the bad smell" (FGD3, Mother).

"When he was finally back home, everyone disappeared in our life, stating they could not accept him back. Even his uncles. I was left alone to care for him. At first it was hard. No-one would even hire me for a small job. But in time, I figured out how to live with him and all the entourage expressed their welcoming sincerest thoughts" (FGD3, Mother).

As time goes by and parents get used to living with their children, they notice improvements to their child's health with his/her development, as one mother shared: *"When he came back, his limbs were shaking to the point that he couldn't eat by himself. But seeing his siblings eating, they taught him, so he is now able to eat, he washes himself, he now requests to go use the toilet and his siblings take him. The only thing I still do for him is washing his clothes. I thank God for having him with us" (FGD3, Mother).*

Table 23: Attitudes towards the de-institutionalization of children with disabilities

Attitude	Strongly agree (%)	Agree (%)	Slightly agree (%)	Neutral (%)	Strongly disagree (%)	Disagree (%)	Slightly disagree (%)	Don't know (%)
'I believe we should transition from institutional care to family and community-based alternatives'	99 (12.3)	371 (46)	196 (24.3)	20 (2.5)	84 (10.4)	9 (1.1)	27 (3.3)	1 (0.1)
'I would consider raising my children with disabilities in the family'	149 (18.5)	424 (52.5)	157 (19.5)	25 (3.1)	41 (5.1)	3 (0.4)	6 (0.7)	2 (0.2)

Having children back in their homes also improved the parent-child relationship. One mother noted: "*It made a significant positive impact. When she was still in the centre, when I visited, she did not seem to recognise me that much. But since she is with us, she easily recognizes you, she interacts with her siblings and other relatives, she is happier than before. It really helped her" (FGD3, Mother).*

Positive improvements were also noted in the parents' own lives. Most parents in focus group 3 admitted that having their child back home removed them from the loneliness they were feeling. "*When she was in the centre, I was homeless. But now I have a decent place to live. She fills our home with joy. We sit and sing with her" (FGD3, Mother). These kids are like our pillar in the society 'igiti cyo kwishingikirizaho muri society'. When people see the HHC team coming to check on them regularly, even the ones with bad intentions change their minds" (FGD3, Mother).*

3.6.3 Attitudes regarding the use of residential institutions for children with disabilities

Participants were also asked a series of questions exploring their attitude towards the use of residential institutions (on a full-time or a part-time basis) as a possible placement alternative for children with disabilities. Despite most participants being in favour of deinstitutionalization, a considerable number held a favourable attitude towards residential institutions for children with disabilities. Results in Table 24 show that 24.2%, 36.2% and 13.4% of participants strongly agreed, agreed or slightly agreed respectively to the assertion "*I believe it is better to raise children with disabilities in residential institutions than in the family and community*". Similarly, participants either strongly agreed (23.8%) or agreed (37%) to the assertion "*I would consider raising my children with disabilities in institutional care for children with disabilities*". Findings from the focus groups allude to the above point of view from parents of children with disabilities. Their perceptions indicate that home-based care and institutional care were preferred by parents as important placement options based on different reasons. They emphasized home care as the preferred strategy, but they also highlighted the challenges faced when caring for a child with disabilities in their home, thus resorting to institutional care.

Parents who have had, or still have, children in residential institutions shared their experiences by highlighting the circumstances that led them to make the decision to place their child in a residential institution. This generated two themes throughout the two focus groups; the inability of parents to face the burden associated with raising a child with a disability and placing their child in an institution in search of a better life. The inability to cope with the challenging life conditions associated with raising a child with disabilities largely influenced their decision to place their child into a residential institution as illustrated below:

"Before, my mother was helping to care for her. When she died, and her father was imprisoned, I was left alone with five children to look after, including her. It became so heavy on me. Through the advocacy of my community, they took her into the centre" (FGD2, adoptive mother).

"When his mother left me, life became hard. The child was moving from one family to the other, until they all got tired. I tried to care for him, but it was really hard on me and the child" (FGD2, Father).

Table 24: Attitudes regarding the use of residential institutions for children with disabilities

Attitude	Strongly agree (%)	Agree (%)	Slightly agree (%)	Neutral (%)	Strongly disagree (%)	Disagree (%)	Slightly disagree (%)	Don't know (%)
'I believe it is better to raise children with disabilities in a residential institution than in the family and community.'	196 (24.2)	293 (36.2)	109 (13.4)	15 (1.8)	18 (2.2)	151 (18.6)	25 (3.1)	2 (0.2)
'I would consider raising my child with disabilities in institutional care for children with disabilities'	192 (23.8)	303 (37.5)	120 (14.9)	12 (1.5)	12 (1.5)	147 (18.2)	20 (2.5)	1 (0.1)

3.6.4 Perceived disadvantages of using residential institutions for children with disabilities

The results in Table 25 show the most frequently reported disadvantages of residential institutions were lack of parental love (38.9%) followed by separation of children with disabilities from their family (34.7%), lack of education and increased risk of acquiring of bad behaviours (28.1%), not getting the same care as a parent would provide (27.6%), children with disabilities feeling uncomfortable with substitutes caregivers (24.9%), being away from the family (17.4%), growing up without knowing the family members (16.2%), risk of violence or harassment from some educators/ caregivers (14%), living as an orphan (6.3%), and living as if they were in quarantine (2.5%).

Parents generally revealed that institutional care brings more challenges than benefits when it comes to the overall wellbeing of children. Despite this, they regarded it as the only viable option because community day care services are not available everywhere.

During focus group discussions, parents argued that family-based care provided personalized care as opposed to institutional care. Parents believed that family-based care gave them the opportunity to provide care that is individualised to a child's needs, offered by the parents themselves instead of someone else. More benefits of family-based care were voiced among the first group of parents who had never placed their child in a residential institution. *"When your child is cared for at home, it is good for him, for yourself as a parent and for his siblings. You have got to show him the love he needs, you need to bond as a parent and a child, and you have the chance to attend to his needs, you give him his medication (if you have a chance to get them)" (FGD I, Father).*

Parents also perceived that meeting the different and varying needs of their child with disabilities could be more possible when cared for in a family than in an institution. *"A teenager requires a lot of energy that requires proper eating. I have noticed a huge change during this pandemic when she is with me. Before, her breasts were not coming out, but they are now developed" (FGD I, Mother).*

Another parent emphasized the fact that the love from a parent is very important in a child's development, and only home care can offer this: *"A child with a disability needs more love to grow. When they are cared for at home, they are surrounded by their parents and siblings, the entire* *family. They play with their siblings, they grow happy" (FGD1, Mother).*

One mother who has two children, one in an institution and one at home, shared why she opted not to place her less severely disabled child in an institution. She reported: *"People have been advising me to put my daughter in an institution. But I said to myself, if I cannot take care of her as her mother, how do I know if others will be able to care for her? If today I cook a meal and she does not eat it, tomorrow I change it and try another one until she can eat. I know very well how her days go. But if she was in an institution, this was not going to be possible" (FGD2, Mother).*

Regarding education, the results presented in Table 25 show that 40% of children with disabilities attend mainstream local schools. This may facilitate their reintegration into their communities and families. However, 54% of participants reported that their child with disabilities does not attend school. Study findings highlight that there are still some barriers such as schools refusing to accept a child with disabilities (37%), affordability of school fees (44.2%), and distance or accessibility of the school (14.7%). Only 4.2% of parents said their child with disabilities does not attend school out of choice, because the family did not want them to go to school.

Regarding the primary caregiver who stays at home with the child with disabilities, mothers were cited as the most common primary caregiver (33%). Other family members also play a very important role as the primary caregiver, particularly older siblings (12.8%), fathers (10.7%) and younger siblings (10.2%). This means that rearing a child with a disability in the community can be challenging as a member of the family has to stop his own activities to stay at home.

Table 25: Reported disadvantages of using residential institutions for children with disabilities

	Frequency	Percentage
Kubura urukundo rwa kibyeyi (Lack of parental love)	314	38.9
Kumutandukanya n'umuryango (Separation from the family)	282	34.9
Kubura uburere + Imicomibi (Lack of education + Bad behaviours)	227	28.1
Kutitabwaho uko bikwiye nkuko umubyeyi yabikora (Not getting the same care as a parent would provide)	223	27.6
Kutisanzura kubabarera (Feeling uncomfortable with substitute caregivers)	201	24.9
Kuba kure y'umuryango (Being away from the family)	140	17.3
Gukura atazi umuryango (Growing up without knowing the family)	131	16.2
Guhohoterwa / Guhutazwa (Violence/Harassment)	113	14
Kubaho nk'impfubyi (Living as an orphan)	51	6.3
Kubaho nk'abari mu kato (Living as if they were in quarantine)	20	2.5
Hari ibigo bibagiran k'aho bibacuruza (There are some residential institutions who trade them)	6	0.7
Don't know	95	11.8

3.6.5 Perceived advantages of institutional care

Even though parents and caregivers support the deinstitutionalization option, they do not have easy access to various services in the community to deliver family-based care in the home. They only receive services such as educational and medical support from residential institutions. As was evidenced by the results presented in Table 26, caregivers/parents generally held the view that institutional care for children with disabilities provides children with acceptable support. Concerning the advantages of residential institutions for children with disabilities, the results show that most of participants had the same viewpoint that children get access to support in terms of education, medical care and nutrition (93.7%) in residential institutions. 38.3% of participants mentioned that children with disabilities feel comfortable and at ease with other children that have similar impairments or challenges. In addition, 11.2% of participants reported that this protects them from persecution and isolation. Furthermore, 19.5% of participants reported that children with disabilities would no longer need to travel long distances for school as they would be schooled within the institution, and 4.1% of them mentioned that caregivers/parents would have enough time to work. Providing these services at home is therefore essential to family-based care.

Qualitative data on the other hand revealed that, when life circumstances became hard on parents, they looked for available alternatives to ensure their children continued to get the support they wished they could offer them. Most of the parents alluded to institutional care as the only alternative that was available to offer a better life to their child. One mother shared about how placing her child in an institution was a difficult decision for her: "*As a parent, thinking of placing your child in an institution is the hardest decision. You have exhausted all resources. You feel bad that you cannot offer a better life to your child. So, you are left with no choice but placing her in an institution so that she can at least have a better life. If I had means to care for her, I would have never put her in there" (FGD1, Mother).*

Similarly, one father shared how he decided to put his child in an institution whilst searching for medical support that they could not afford: "*My child was too sick, with rigid muscles and he couldn't eat or move. I was afraid he might die. They advised me to take him to an institution for treatment. Everyone was telling me that he will not live for long, that is why her mother left. I accompanied him to the centre, and he started getting intensive treatment. I kept visiting him" (FGD2, Father).*

One key informant further expressed a typical view of many parents: "*for parents, residential institutions help them continue working their daily work that contributes to the welfare of their families, after which they are able to take better care of their children".*

Table 26: Reported advantages for the use of institutional care

	Frequency	Percentage
Ubufasha buhagije (ubuvuzi, uburezi, ibyo kurya) (Adequate assistance (medical, educational, nutritional))	756	93.7
Barisanzura bakiyumva mu bandi bahuje ibibazo (They feel comfortable and feel at ease with others)	309	38.3
Ntavunika mu rugendo ajya kwiga (He/she no longer does long journey to go to school)	17	2.1
Bibarinda itotezwa n` akato (It protects them from persecution and isolation)	90	11.2
Uwitaga kumwana agira igihe cyo gukora (The caregiver has time to work)	33	4.1
Don't know	6	0.7

3.6.6 Attitudes towards the use of residential institutions for children with severe disabilities

Regarding the most appropriate form of care for children with severe disabilities, results in Table 27 show that fewer percentages of participants either strongly agreed (26.4 %) or agreed (26.5%) that family care is the appropriate form of care for children with a severe disability. Furthermore, 23% and 51.4% of participants either strongly agreed or agreed respectively that alternating between family care and institutional care (50-50% of the time) was the appropriate form of care for children with severe disabilities. In particular, institutional care was perceived by parents as helpful in situations where the child had a severe disability that could be hard to take care of at home. One father explained: "*Although my son is 9 years old, he is still at the toddler level. He is kept in diapers, he sleeps on warm, special bedding. These would be hard to obtain if he was staying at home" (FGD2, Father).*

Table 27: The most appropriate form of care for children with severe disabilities as reported by participants

I believe the most appropriate form of care for children with multiple or a severe disability is.....	Strongly agree (%)	Agree (%)	Undecided (%)	Disagree (%)	Strongly disagree (%)
Family care (100% of the time)	213 (26.4)	214 (26.5)	134 (16.6)	216 (26.8)	30 (3.7)
Alternating between family care and institutional care (50-50 % of the time)	186 (23)	415 (51.4)	98 (12.1)	89 (11)	19 (2.4)

Among the parents who participated in the focus group, family-based care was not regarded as suitable for children with complex needs although it was the preferred option by most of them. They noted the difficulties associated with family-based care, particularly when children are affected by complex needs. These worries were mainly voiced among the second group of parents whose children are still in residential institutions. They worry about not being able to offer to their child the best care they might receive in residential institutions because they lack the means to do so, as one father remarks: *"I sit and imagine when my child will be back, to be raised by a stepmother, I imagine the life he was living and what is awaiting him. He requires constant care, he cannot move on his own, you must always do it for him. He sleeps in special bed covers. I can't afford these" (FGD2, Father).*

The same worry was shared by most parents, especially when it comes to medical support offered to children with complex needs. "*Kids in residential institutions get regular physiotherapy, they get the proper chairs, their mattresses are changed frequently, and they have someone to look after them. In the morning, they are in one room, when it gets dirty, they change it, in the afternoon they go in another room.These facilities are not available at home" (FGD2, Father).*

3.6.7 Perceived parental and family capacity to provide care for children with disabilities in a family

Participants were asked whether their own parental and family capacity to provide care for children with disabilities was a facilitating factor or a barrier to reintegration. Findings indicate most participants (77%) did not have the required capacity to care for their child within their family. This was based on the responses from participants who agreed (36.3%) or strongly agreed (40.3%) that their family lacks the financial and material resources needed to take care of a child with disabilities within the family. In addition, the perception of 58% of participants was that raising a child with a disability in a family would increase their family poverty; 33.5% of participants agreed and 24.5% strongly agreed to this assertion. On the other hand, 30% think that raising a child with disabilities within their family does not increase poverty levels.

Employment status and source of livelihood also influenced the way parents and caregivers think about caring for children in their families. A considerable proportion of parents (44.9%) strongly believed their jobs would be negatively affected if their child with disabilities was raised within the family. Furthermore, 66.5% of participants thought that when a child with disabilities is raised in a family, it would require one parent to stop working to take care of him/her. 62.6% of participants reported that they needed someone to take care of the child with a disability while they are at work. Moreover, 52% revealed that they would not have time to take care of other members of the family when a child with a disability comes home.

Table 28: Perceived parental and family capacity to provide care for children with disabilities in a family

Main barriers reported	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I will not have time to take care of other members of the family if the child with a disability lives at home	57 (7.1%)	256 (31.7%)	74 (9.2%)	215 (26.6%)	205 (25.4%)
I need someone to take care of my child with a disability while I am at work or I am going through normal life activities and I have to work	25 (3.1%)	174 (21.6%)	103 (12.8%)	322 (39.9%)	183 (22.7%)
Fear - I'm afraid I can't take good care of a child with a disability at home	46 (5.7%)	268 (33.2%)	22 (2.7%)	265 (32.8%)	205 (25.4%)
Confidence — I am confident that I can take care of my disabled child at home	36 (4.5%)	113 (14%)	118 (14.6%)	389 (48.2%)	151 (18.7%)
Raising a child with disabilities in the family is a burden on the family	32 (4%)	236 (29.2%)	28 (3.5%)	288 (35.7%)	223 (27.6%)
I think when a disabled child is raised in a family, it requires one parent to stop working to take care of him/her	32 (4%)	178 (22.1%)	60 (7.4%)	361 (44.7%)	176 (21.8%)
My family lacks the capacity (money, resources) needed to take care of a child with disabilities within the family	47 (5.8%)	108 (13.4%)	34 (4.2%)	293 (36.3%)	325 (40.3%)
I think my job will be negatively affected if my child with disabilities is raised within the family	2 (0.2%)	21 (2.7%)	56 (7.2%)	349 (44.9%)	349 (44.9%)
Raising a child with a disability in a family will increase our family poverty	53 (6.6%)	189 (23.4%)	97 (12%)	270 (33.5%)	198 (24.5%)

3.6.8 Perceived community and family readiness to receive children with disabilities from residential institutions

In regards to perceptions towards the readiness of the community and families to receive children with disabilities from residential institutions once they are deinstitutionalized, respondents highlighted the need to consider the availability and affordability of services in their community. Regarding availability and cost of community-based services compared to services provided to children with disabilities in residential institutions, 77% of participants agreed that there are no available schools to accommodate children with disabilities if they come to live in the family. 71% of participants were of the view that an absence of special equipment for their children with disabilities would make it hard to raise them in the family. Most participants (57.7%) reported the condition of their village (mountains, valleys, lack of roads) would not allow a child with a disability to be raised in the family. Furthermore, most of the participants (63.4%) thought that keeping a child with a disability at home requires making a lot of changes to the home which families are unable to afford, while other participants (60.5%) thought transportation or access to school or health services would be a problem for a child with a disability.

The access to health services appears to be a serious concern and should be prioritised in the program supporting family-based care for children with disabilities. Parents who participated in the focus group discussion expressed difficulties in affording medical care needed by their children. This was shared across all three focus group discussions. As a consequence, children were denied opportunities for treatment as several parents shared: "*He has been missing his treatment because I couldn't afford to buy it regularly, his joints were rigid, and I took him for treatment. I paid 70.000 RWF in one month, and I had to request for a discharge because I couldn't afford the cost anymore. Had I had more means, I would have stayed with him to get proper treatment" (FG1, Father). "I went to K hospital because there was a specialist doctor. He told me he could see my child every month. I only took him there once because I couldn't afford the cost" (FGD2, Mother).*

Another pressing need that was identified by parents in the focus group was the need for schooling and education. It came out from the discussions that parents were faced with a lack of schooling opportunities that would adequately cater to the special needs of their children. Where parents had tried using the existing school system, their child experienced discriminatory practices that made it difficult for them to thrive. This was exacerbated by the long distance between parents' homes and the existing school for special needs children which posed big challenges to accessibility as one parent noted: "*You see, schools for children with disabilities are few and are located far from our homes. And we do not have enough means to take our children to these schools. The child is kept at home not because of our will, but because of lack of opportunities" (FGD1, Mother).*

Parents who tried to take their children to regular schools ran into difficulty by the apparent lack of infrastructure needed. "*I went into one school to enrol him. But I looked at him, he is in a wheelchair, if he needs to use the toilets, he won't be able to do it on his own..., so I gave up" (FGD3, Father). "I asked one teacher who knew my child if he could take him into his class. He dismissed the idea. He told me "I have a class of 40, how can I look after him? Another challenge, you go to the school or health facility and find stairs all over the place. How can you reach there with your child in a wheelchair?" (FGD 2 Father).*

Having a decent place to live that can accommodate the special needs of children with a disability was another daily living need identified across the three FGDs. Most participants highlighted the difficulties associated with mobility when staying in such places as one parent articulated: "*Most families with children like this stay in amanegeka, inaccessible even in a wheelchair. They resort to carrying their children on their backs. But as mine is tall and heavy now, when I put him on my back, he cries out in pain" (FGD2, Mother)*. Such places also pose a challenge for the daily needs of children with disabilities and their potential development. "*We live in a tiny room, having to share that same room with a child with disability is a challenge. Look, we live in a very crowded place "utujagari" where a child does not even have a place to even learn to crawl" (FGD1, Father).*

Lack of consideration towards issues affecting families with children with disabilities was strongly highlighted by parents in the focus groups, predominantly in group 3. In particular, parents feel unacknowledged by the local authorities when it comes to being given access to essential services as one parent remarks: "*Some time ago, there was milk donation for children in our cell. We went to the sector office, there was this mother whose child badly needed milk. The chief of the cell stood up and stated that the milk was for children, and not for "ibimuga"" (FGD3, Mother)*. Such a lack of consideration was also felt in terms of accessibility to essential services: **"***I was put in the third category of Ubudehe, which means that my child is also in that category. Yet, he is unable to do anything because he has multiple disabilities. When there is any support that he would otherwise benefit from, he won't benefit from it because of being in that category" (FGD3, Father).*

Table 29: Perceived community and family readiness to receive children with disabilities from residential institutions

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
There is insufficient support from local religious authorities for children with disabilities living in families	45 (5.6%)	171 (21.2%)	86 (10.7%)	279 (34.6%)	226 (28%)
Education - no schools available to accommodate children with disabilities if they come to live in the family	43 (5.3%)	58 (7.2%)	83 (10.3%)	297 (36.8%)	326 (40.4%)
Special equipment will not be available for my child to raise them in the family	53 (6.6%)	56 (6.9%)	122 (15.1%)	269 (33.3%)	307 (38%)
Health services are not easy to find for children with disabilities raised in the family	44 (5.5%)	40 (5%)	69 (8.6%)	265 (32.8%)	389 (48.2%)
I will not be able to pay for the needs of a child with a disability	33 (4.1%)	36 (4.5%)	82 (10.2%)	286 (35.4%)	370 (45.8%)
Keeping a child with a disability at home requires a lot of change in the home we live in which our family is unable to afford	45 (5.6%)	94 (11.6%)	156 (19.3%)	284 (35.2%)	228 (28.3%)
The condition of our village (mountains, valleys, lack of roads) will not allow the implementation of the plan to raise a child with a disability in the family	20 (2.5%)	160 (19.8%)	161 (20%)	279 (34.6%)	187 (23.2%)
In my area, transportation or access to school or health services will be a problem for a child with a disability	13 (1.6%)	148 (18.3%)	158 (19.6%)	295 (36.6%)	193 (23.9%)
I am concerned about the safety of our family and children with disabilities when they come home	70 (8.7%)	259 (32.1%)	130 (16.1%)	182 (22.6%)	166 (20.6%)

3.6.9 Perceived potential stigma from the community towards reintegrated children with disabilities and their families

Concerning stigmatization, findings indicate that in the communities where 81.2% of the participants live, people with disabilities are called degrading and dehumanising names and sometimes treated in a way that makes them feel worthless. 48.9% of participants revealed that some members of their family (small or large) cannot consent to providing care to a child with a disability, while 41% reported that their family would be embarrassed or ashamed to have a child with a disability at home. Interestingly, responses from more than half of participants (55.4%) indicated that having a child with disabilities at home would not cause them any embarrassment or feeling of shame.

Table 30: Perceived potential stigma from the community towards reintegrated children with disabilities and their families

Main barriers reported		**Strongly disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly agree**
Stigma	Our family would be embarrassed or ashamed to have a child with a disability at home	68 (8.4%)	379 (47%)	29 (3.6%)	207 (25.7%)	124 (15.4%)
	Some members of our family (small or large) cannot consent to provide care to a child with a disability	49 (6.1%)	292 (36.2%)	71 (8.8%)	244 (30.2%)	151 (18.7%)
	Where we live, there are some beliefs, either traditional or religious, that could backfire on children with disabilities	57 (7.1%)	359 (44.5%)	114 (14.1%)	146 (18.1%)	131 (16.2%)
	Where we live, people with disabilities are called names or treated in a way that makes them feel worthless	8 (1%)	103 (12.8%)	41 (5.1%)	416 (51.5%)	239 (29.6%)

3.6.10 Determinants of favorability towards the deinstitutionalization of children with disabilities

Binary logistic regression models were run to predict favourability towards the deinstitutionalization of care for children with disabilities. Some factors (being from the sector with no residential institution; gender, education and age of respondents; age of children with disabilities; parental status - alive/dead) were not found to be associated with favourability levels towards deinstitutionalization.

Table 31 shows that parents living in urban areas were more inclined to favour the deinstitutionalization of care for children with disabilities compared to rural areas (OR=1.647, p<.01). According to the parent/caregiver's marital status, divorced and separated individuals had lower chances of favouring deinstitutionalization of care for children with disabilities compared to single individuals with OR=.382, p<.05 and OR=.609, p<.01, respectively. Parents/caregivers with subsistence jobs and reported other jobs had more chances of favouring the deinstitutionalization of care for children with disabilities compared to those unemployed with OR=1.725, p<.01 and OR=2.108, p<.01, respectively. Parents of children with a lower functional disability score (Washington Group) favoured deinstitutionalisation by OR=1.364, p<.01. Parents with negative attitudes towards children with disabilities were less likely to favour the deinstitutionalization of children with disabilities compared to those with positive attitudes (OR=.472, p<.05). Similarly, parents with negative feelings towards children with disabilities had .369 times the odds of favourability towards the deinstitutionalization of care for children with disabilities compared to positive feelings. Parents with children who never lived in a residential institution (fulltime or part-time) had more likelihood of favouring the deinstitutionalization of care for children with disabilities compared to parents whose children lived in a residential institution (OR=1.918, p<.001). Furthermore, low parental skills and family capacity to provide care of children with disabilities were less likely to favour deinstitutionalization compared to those with high parental skills and family capacity to provide care of children with disabilities (OR=.697, p<.05).

Table 31: Bivariate analysis of the predictors of favorability towards the use of deinstitutionalization for children with disabilities

Variables		**Favourability towards deinstitutionalization**		**Bivariate OR**
		Low favourability (%)	**High favourability (%)**	
Sector with residential institution	yes	122 (54.7)	101 (45.3)	
	no	315 (53.9)	269 (46.1)	1.032
Residence	rural	306 (58.5)	217 (41.5)	
	urban	131 (46.1)	153 (53.9)	1.647**
Gender	male	118 (54.1)	100 (45.9)	
	female	319 (54.2)	270 (45.8)	1.001
Age of respondents	less or equal to 34 years	119 (56.9)	90 (43.1)	
	35-47 years	207 (52.5)	187 (47.5)	.903
	48 years and above	111 (54.4)	93 (45.6)	1.078
Education	no formal education	100 (52.4)	91 (47.6)	
	primary & other training	278 (55.4)	231 (44.6)	.884
	secondary	44 (49.4)	45 (50.6)	1.124
	university	6 (66.7)	3 (33.3)	.549
Marital status	single	21 (53.8)	18 (46.2)	
	married	275 (57.7)	202 (42.3)	.710
	separated	39 (68.4)	18 (31.6)	.609**
	divorced	9 (30)	21 (70)	.382*
	widower	35 (46.1)	41 (53.9)	1.933
	cohabitation	58 (45.3)	70 (54.7)	.971
Parent/caregiver working status	unemployed	292 (60.3)	192 (39.7)	
	Employed/salary	6 (50)	6 (50)	2.535
	Subsistence job	82 (46.9)	93 (53.1)	1.725**
	others	57 (41.9)	79 (58.1)	2.108***
Age of children with disabilities	less or equal 6 years	128 (55.7)	102 (44.3)	
	7-12 years	180 (52.2)	165 (47.8)	1.150
	13 years and above	125 (55.1)	102 (44.9)	1.024
Functional disability (Washington Group)	Scores	mean=1.8884	mean=1.6721	1.364**
Parental status	Both parents died	2 (33.3)	4 (66.7)	
	Both parents alive	379 (54.1)	321 (43.9)	.423
	One parent died	56 (55.4)	45 (44.6)	.402
Attributes ascribed to children with disabilities	positive	58 (38.2)	94 (61.8)	
	neutral	5 (50)	5 (50)	1.121
	negative	338 (52.4)	307 (47.6)	.472*
Feelings experienced when thinking of children with disabilities	positive	79 (42.9)	105 (57.1)	
	neutral	20 (54.6)	17 (45.4)	1.105
	negative	308 (67.6)	190 (32.4)	.369**
Positive conceptualization: I think children with disabilities can grow up like everyone else and continue their way of life	Never or hardly ever	17 (51.5)	16 (48.5)	
	Most or some of the time	420 (54.3)	354 (45.7)	.896
Ever lived in a residential institution (fulltime or part-time)?	yes	140 (65.7)	73 (34.3)	
	no	297 (50)	297 (50)	1.918***
Participation of children with disabilities in household activities	yes	238 (55.5)	191 (44.5)	
	no	199 (52.6)	179 (57.4)	1.121
Parental skills and family capacity to provide care of children with disabilities	high	170 (44.4)	213 (55.6)	
	low	267 (63)	157 (37)	.469***
Stigmatization	high	160 (50)	160 (50)	
	low	277 (56.9)	210 (43.1)	.758
(***) p<0.001, (**) p<0.01, (*) p<0,05				

3.7 Knowledge about Residential Institutions for Children with Disabilities

3.7.1 Awareness about the availability of institutional care services

There seems to be institutional care service establishments in many communities of Rwanda because only 20% of key informants said services are unavailable whereas 80% were aware of services within the vicinity of their respective communities. Only one of the respondents affirmed that his community has more than two residential institutions, an assertion that seems to indicate plausible push and pull factors that may lead to the development of residential institutions for children with disabilities in some Rwandan communities.

3.8 Practices regarding Community Services and Residential Institutions for Children with Disabilities

3.8.1 Having ever placed a child with disabilities into an institution

Participants were asked if any child with disabilities in the family has ever lived in a residential institution. The results summarized in Table 32 show that 73.6% of parents revealed that their child never lived in a residential institution and they stayed in their communities, while 26.4% reported that their child had lived in a residential institution on a full-time or a part-time basis. Only 5.1% of participants reported that their child with disabilities has ever lived in a residential institution on a full-time basis and only 2.1% reported their child with disabilities to be living full-time in a residential institution during the survey. 23.9% of parents reported that their child with disabilities had a link with a residential institution for part-time stays mainly for medical or educational services.

Table 32: Having ever placed a child with disabilities into an institution

		Frequency	Percent
Ever lived in a residential institution (full-time or part-time)	No	594	73.6
	Yes	213	26.4
Child with disabilities ever lived full-time in a residential institution	No	766	95
	Yes	41	5.1
Child with disabilities currently living full-time in a residential institution	No	790	97.9
	Yes	17	2.1
Child with disabilities linked with a residential institution for part-time stays	No	614	76.1
	Yes	193	23.9

3.8.2 Decision to place children with disabilities into residential institutions

The decision of whether to place children with disabilities into institutional care seems to be determined by a range of factors. These include, but are not limited to, proximity to the institution; availability of financial support to access institutional care services; the quality of services provided; the level of parents' awareness; the personal relationships between parents and the institution, and more. Table 33 highlights some of factors respondents report to have influenced their decisions.

Table 33: Factors influencing the decision to place or not to place a child with disabilities in a residential institution

Factors influencing the decision to place a child with disabilities in an institution	Factors influencing the decision not to place a child with disabilities in an institution
● NGOs assist some parents to take their children to a residential institution and not keep them at home. ● Availability of the institution near parents is also the only information source for parents. ● Parents opt for a residential institution because they can provide rare services, education and therapy. ● Some parents take their child with disabilities to a residential institution because they are a burden at home. ● Some parents do not have information about what is being done in residential institutions, or do not care. ● At least children with disabilities can get affection and food in an institution. ● Some families expect assistance from residential institutions. ● Some institutions look for support and donations though the presence of children with disabilities. ● Parents take their child with disabilities to a residential institution for socialization and interaction with peers. ● In the poorest communities, they prefer the child to be taken care of in a residential institution.	● Lack of confidence in services provided by some of the residential institutions. ● In some residential institutions there are no qualified personnel and resource capacity to offer quality services. ● Institutions expect parents to pay and yet parents are not able to afford the cost because they are poor. ● Some residential institutions are not within reach of some families, or it is costly to take a child with disabilities there. ● Some families do not have sufficient information on residential institutions and their services. ● Some families are ignorant of the child with disabilities' needs, rights and therefore the importance of institutions. ● Some residential institutions do not have adapted programs (curriculum), especially for mental challenges. ● Residential care institutions are very expensive and owners use income for the institution than professional services. ● Some parents do not view them as professional units. ● Parents who view disability as a permanent inability also regard residential institutions as a waste of time for children with disabilities.

The testimonies indicate that children with disabilities are caught in a situation whereby their institutional and/or family care are neither centrally guided nor quality-controlled options. This is because decision making is left to the family jurisdiction, solely dependent on the family's means, levels of understanding and service provision for children with disabilities.

The views indicate a range of reasons why parents decide between institutionalization or family care for their child. The prevailing viewpoint from professionals (key informants) was that most families prefer to have their child with disabilities in institutional care because most homes are not adequately prepared to care for them, in terms of mind-set, resource means, and external support. Accordingly, while some parents go to the extent of spending large amounts of money for institutional care (despite the questionable quality of services), many more opt for family care because they cannot afford, or are not aware, of institutional services.

3.8.3 Seeking support from external people/ institutions to take care of the needs of children with disabilities

Participants were asked who they have ever sought support from (external people/ institutions) to take care of the needs of their child with disabilities. More than a half (56%) revealed they have never sought support from an external person/institution. The most common source of support mentioned was from extended family members (53%). Health care providers were reported to play an important role, with 40.4% of parents reporting to have, at some point in time, reached out to health care providers, including specialist medical services. Another important category were friends/neighbours (17.8%) for providing external support.

Table 34: People/institutions approached to seek support in the care of the needs of children with disabilities.

Person/institution approached to seek support in the care of the needs of children with disabilities	Extended Family	428 (53%)
	Friends/neighbours	144 (17.8%)
	School	94 (11.6%)
	Health care providers	205 (25.4%)
	Specialist medical service (hospital, specialist therapist)	121 (15%)
	Local services	75 (9.3%)
	NGOs	12 (1.5%)
	Religious organisation	5 (0.6%)
	No one	452 (56%)
	Other	14 (1.7%)

3.8.4 Interactions of children with disabilities within their families and communities

Key informants responded to the question regarding the interaction of children with disabilities within their families and communities. Only one respondent agrees that it is difficult to interact with children with disabilities at both institutional and family levels. However, all respondents affirm that the level of interactions with family members, siblings, peers and neighbours is determined by the category of the disability and associated challenges. One respondent who works in an institution for children with hearing disabilities expressed his difficulties with interacting as "*Some children who are deaf do not know Rwandan sign language — I am blocked as I have no sign language skills...*"

Respondents that interact with children with different difficulties, especially those with cognitive and other related challenges, expressed their difficulties at both institutional and family levels. "*For many of the children, the interaction is difficult due to the categories and level of disability .... I don't find it difficult to interact with children with disabilities because I now have many years in the field, however when it comes to those with a hearing impairment.... for many of the children, the interaction is difficult due to the type and level of disability, for families it is still a challenge as long as they have many problems.*"

The difficulties in interacting with children with disabilities are expressed by respondents in many ways, and are accordingly generated in the following sources observed in residential institutions and communities:

- *Inadequate human and material resources required in services for children with disabilities (education, therapy, etc.)*

- *Inappropriate service provision largely influences interactions with children with disabilities in residential institutions, notably the communication channels, teaching/learning curriculum and resources.*

- *Inappropriate cultural and social attitudes or expectations towards people with disabilities. Accordingly, the families and/or the general community mindset determines the level of difficulties in interacting and/or provisions to children with disabilities.*

The respondents' views seem to suggest the key determinants underlying the level and quality of interactions with children with disabilities are engendered on the one hand by the established family or community mindsets and on the other by the economic capacity of family members or the community. Both combine to determine the extent to which children's disabilities are interpreted and how the associated challenges are communicated, thereby determining the provisions and/or support is reserved for children with disabilities' services at both family, community, and institutional levels. The validity of respondents' claims above, however, on challenges in interacting with children with disabilities at family, community and institutional levels as well as the related mitigation strategies, can also be qualified in parallel with challenges and enablers of services for children with disabilities.

3.8.5 Comparative treatment practices and access to basic services

The respondents did not clarify the exact ways in which children with disabilities are treated in families and communities, however, they all agreed that they were not being treated like other children. In a close discussion with respondents, it was disclosed that the treatment ranges from overprotection to mistreatment and outright marginalisation and rejection.

Overprotection

Children with disabilities are overprotected by treating them as delicate or sickly family members not allowed to participate in family activities or chores, and permanently supported with feeding, dressing, and cleaning, even when he/she could be facilitated to learn how to do it themselves. This was often expressed in words such as "Ntacyoyakwimarira, ntashoboye, n'uwange.". Respondents reported a case where a house worker was hired for a grown-up youth with a disability, and cases of children with disabilities kept indoors permanently. One of the respondents summed up the treatment of children with disabilities; *"In my community, children with disabilities are not treated equally as other children, and I have not seen any difference from girls to boys".*

Marginalisation

On the other hand, marginalisation of children with disabilities in families and communities is seen in many ways, ranging from letting the child roam around the community without any concern from the family, to diverting the attention to the siblings and neglecting the child with disabilities. Marginalisation tendencies include:

- *Not caring whether the child with disabilities is fed or not.*
- *Not knowing where the child with disabilities is during the course of the day or night.*
- *Sidelining the child with disabilities due to their inappropriate dressing or cleanliness.*
- *Abusive or improperly identifying the child with disabilities, e.g, ese cyagiye he noneho?*
- *Abusive punishments for misbehaviour and errors, with no correction measures.*

The way families and communities treat children with disabilities has bearing on the extent to which family members understand disability and the child with disabilities' potential, as well as the availability of services for children with disabilities and means of accessing them. Respondents highlighted several explanations for this:

- *Many children with disabilities do not access an education due to the financial situation and mindset of their parents.*
- *Children with disabilities sometimes do not access healthcare services due to their disabilities, e.g. deaf children who do not communicate with parents and health workers.*
- *Families generally think that girls with disabilities are more endangered than boys with disabilities, as are more at risk of being bullied at school, raped or subject to other abuse.*
- *Everybody thinks that helping children with*

disabilities is an act of charity whereas it is their right. They have the right to education, health and all the basic needs of life.

- *While children under 5 years of age without disabilities are given support by local leadership to prevent malnutrition, those with a disability in the same class are not considered when they are over 5 years old, and this puts them at risk of malnutrition.*

Mindset, level of awareness, and available resources, all seem to determine the families' treatment of children with disabilities, and their abilities to seek for provisions that would change the child's life for the better.

3.8.6 Availability, sufficiency and accessibility of resources to support children with disabilities

Respondents' views on the availability, sufficiency and accessibility of resources for children with disabilities generally indicate dissatisfactory provisions in residential institutions and communities due to generalised deprivation and inadequacies at both family and community levels. Their perceptions and ideas are interpretable from the language illustrated in Table 35.

Table 35: Key informants' views on resources needed to support children with disabilities to live productive lives

Views on the availability of resources	Views on the sufficiency of resources	Views on the accessibility of resources
● Truly, there are no special resources available for children with disabilities. ● It is still a challenge to children with disabilities, families & institutions. ● Residential institutions use what is available to them. ● Our residential care institution only helps parents of children with disabilities to access lucrative cooperatives so they can cater for the children in school and in families. ● Some are available but they are not affordable for many.	● At the lowest possible level. ● There is only one school with limited human and material resources available for children with disabilities, which was initiated by an association of parents. ● They are not enough. ● Even where food and other basics are provided, they are not sufficient and of suitable quality. ● The available residential institutions are far from the children with disabilities.	• Parents run around looking for external support such as orthopedic services, because they are not able to afford them. • Some children with disabilities can access basic services, but many end up dropping out of school because they cannot afford basic services. • The residential institutions only provide food, books, pens, notebooks, medical assurance to children with disabilities who can afford to come to school. • We have children with disabilities who cannot access our services because they are not in our proximity.

Clearly, respondents seem to picture a situation whereby availability, sufficiency and accessibility of resources for children with disabilities to live a productive life is actually entangled within a vicious cycle of generalised misunderstanding or misinformation about the disability and needs of children with disabilities, deprivations or continuous need for external support, and poor and/or inadequacy of services and resource provision for children with disabilities at both family, community and institutional levels. In fact, this context seems to intersect the lives and situation of children with disabilities in Rwandan communities and residential institutions.

3.8.7 Provision of resources, policy, support and attitudes towards children with disabilities

The inadequacies were reiterated again by all interviewed professionals in terms of resources, policy, and support provisions for children with disabilities. They highlighted the existence of sound policies that are not visible on the ground where the children with disabilities are, and how attitudes of family and community members continue to discourage the provision of support for children with disabilities. The respondents' views are disaggregated in Table 36.

Table 36: Respondents' views on challenges in terms of resources, policies, support, and community attitudes towards children with disabilities

Resource provision	Policy provision	Support provision
• There are not enough resources. • Resources are not available. • We are challenged in terms of resources. • No appropriate educational resources, curriculum, etc. • Resources are not enough to satisfy the needs of children with disabilities at the centre. • In terms of resources, the centre has some but they cannot be used in home programs for children with disabilities.	• The policy is well established but actions are poor, • Policies are well written and kept somewhere. • Good policies are there but not implemented. • The policymakers do not consider the needs of children with disabilities, including their schooling. • We have good policies and procedures, but hardly any related actions. • There are challenges on resource policies	• Support is still insufficient. • The support budget is still at a low level. • Support is not sufficient to satisfy the needs of children with disabilities. • PWDs' cards facilitate support, but children with disabilities do not have them. • Due to limited budgets, institutions only do what they can, but not all that is necessary. • The support we give children with disabilities cannot satisfy their welfare and needs.

It is easily deducible from the respondents' testimonies tabulated above that the challenges observable in residential institutions and communities are also a consequence of misconnections between policy strategies at national and local levels, and attitudes about children with disabilities that cannot change at family and community levels.

3.8.8 Facilities supporting the integration of children with disabilities into the community

Despite the challenges which may seem overwhelming and insurmountable, respondents were able to identify a range of enablers that have helped change the lives of children with disabilities, such as:

- Some NGOs have played a key role in changing the mindset of family members.
- Local leaders in charge of social affairs play an important role in changing the mindset of community members by mobilizing resources and services for families of children with disabilities e.g., assistive resources, funds for cooperatives and associations for parents of children with disabilities.

- In some communities, community-based rehabilitation takes place (CBR/ CBID) through NGOs, religious groups or churches and enables children with disabilities to develop and live a meaningful life.
- Some members from local mainstream school leadership (parents' committees) contribute to changing mindsets of parents and the community by mobilizing resources and collaborations that support the integration of children with disabilities into schools and communities.

During personal discussions with respondents, they all agreed that by identifying, enlisting, and enhancing all enabling factors available at family and community level, a way forward that requires minimum investment can be found to identify solutions to the challenges facing children with disabilities and their families.

According to the respondents, the main enabling factors are classifiable in terms of support, available knowledge, and understanding. This influences the provision of support for children with disabilities, for example, with the backing of parents, organizations and other stakeholders, some infrastructure, resources, and services can be developed. The main enabling factors include:

- Awareness, knowledge, and skills acquired through trainings as well as experience accumulated over a period of time.
- Moral and material contributions from workmates, parents and other stakeholders closely concerned with the achievements of children with disabilities.
- The organization's vision, mission, and resolve to promote the welfare and development of children with disabilities.

Apparently, the support available to residential institutions and families of children with disabilities is quite minimal or hardly worth considering. It varies from parents' tuition fees to support from local, external donors and agencies. The respondents did not clarify how the support is organised, distributed, or managed, however it is apparent that much of the support is bestowed in the form of payment by parents and sponsors for services offered to children with disabilities, as well as material and financial donations by international organizations and agencies. All reported dependence from organizations and agencies (notably UK agencies, HI, CBM, and EU) to support infrastructure, educational resources, and staff training. Only 60% reported to be support by the government, either directly or through local (district) funding. Only two residential institutions reported to be in receipt of support from the government through salary payments for some of their staff, most likely because they fulfil the conditions for a government subsidy ("Écoles conventionnées").

3.8.9 Main challenges in providing services for children with disabilities

Clearly, there seem to be many more challenges than enablers when providing services to children with disabilities, and those cited by key informants seem to be recurrent and exist across all lives and programs for children with disabilities in communities and residential institutions. Some of the main challenges reported by respondents include:

- *Prevailing negative attitudes about disability within families and society in general.*

- *Generalized deprivation in families and poor knowledge on disability or community misunderstanding of disability.*
- *Inadequately qualified staff and material resources in educational institutions.*
- *Programs in residential institutions that emphasize theory more than practice in health, rehabilitation, and training.*
- *At family level, unqualified house girls (hardly any house boys), family members (grandmothers, old aunties, siblings, etc.) are made to care for children with disabilities while parents attend to household chores. Often, the tasks are rejected or conducted with disinterest by non-family members, while family members carry out tasks because they are culturally obliged to support disadvantaged family members.*
- *Ordinary schools are often unprepared to accommodate children with disabilities because of inadequate infrastructure, resources, curriculum, and dominant attitudes among staff and management.*

As highlighted in the previous section, challenges exist when delivering activities and services for children with disabilities in families and communities and residential institutions. One of the respondents put it this way: *"The challenges are too many ....: house girls and boys don't like to work with the families that have a child with disabilities, normal schools don't welcome them, siblings are tired, parents separate, or one leaves the family and disappears completely, leaving the challenge to the partner. Parent organizations are often the common initiative to cater for their children with disabilities, but the related demands are equally huge — rent for place of work — standardization costs of the place of work.... costs of human and material resources".*

The overarching consensus is that taking care of a child with disabilities is possible but challenging because of many fundamental factors, including needing to dedicate as much time as possible to care for the child and help them with various tasks (therapy, education, health care, feeding, etc). A multi-disciplinary team of expert staff are often unaffordable, and the means to procure services and resources are often financially out of reach.

Although the respondents collectively underline the persistence of challenges in programs for children with disabilities, they also point out various mitigation initiatives in addressing the challenges, highlighting outright determination and resolve among parents and community members. The prevailing conditions are summed up by one informant who is a member of an institution management committee: "*I don't have answers to all children with disabilities' problems, but I say to myself: "be patient you are not the only one ...." in terms of infrastructure, we use what is available even though it is not enough .... for additional skills I tried to read and do research online on caring for children with disabilities ... we maximize as much as possible. .... we benefit from NGOs' training programs, and the little support from children's families ... we also train the parents on basic therapeutic skills so that they offer their support."* Most of the respondents pointed out that parents and residential institutions have found themselves in a situation where they "do what they can with the little means available, though they wish they could do better".

Another highlighted challenge was related to healthcare. Parents in focus group discussions noted a widespread issue relating to a lack of healthcare that is respectful to the needs of children with a disability. They shared the following: *"the most difficult issue is getting him the medical care required. When you go to the doctor, you get overlooked only because your child has a disability. I recently took him to G. hospital. The doctor prescribed him a plaster. Because it is so hard for me to carry* *him, I arrived at around 5pm but the healthcare provider was still in the office. When he saw me, he shouted at me and said "Madam, genda sinakira abanyabibazo" as in to say "go away, I don't receive problematic cases". And he refused to take the doctor's prescription. My heart was aching. My child weighs heavily, I cannot carry him for long, and I couldn't go back home. I spent a night there, the following day I went back to beg, and he was able to put the plaster on, but he saw me last…Removing the plaster was another story, this time, I had to have my local authorities involved and they called another centre for my child to be treated" (FG3, Mother).*

The following parent also experienced less respectful care for her daughter. Similar to the case above, these discriminating practices were also demonstrated by healthcare providers. She narrated it this way: *"My daughter was spitting blood. I got a transfer to K hospital. Because she could not sit, she had to be kept on a "brancard". A healthcare professional came to us and saw my child and stated: is this 'ikirimarima' who is sick? Even normal persons have not yet been received, let alone this one. Take her back. The nurse accompanying me tried to advocate for me in vain. We went back without her getting treated. I was so sad on the way back, thinking of the two weeks that we spent waiting for this transfer, thinking of all the wasted time and money..." (FG3, Mother).*

In addition to being disrespectful and discriminatory, parents viewed the hospital infrastructure to be inadequate in responding to the needs of children with disabilities. This mother shared her experience: *"My main concern is her medical care. It is so tiring. Look, my child is 11 years old, I can no longer carry her on my back. You arrive at the hospital, no one cares, she cannot sit, none of her body parts function properly, you cannot hold her for long, yet you are meant to wait in a queue" (FG3, Mother).*

3.9 The Impact of COVID-19 on the Care of Children with Disabilities and their Families

The COVID-19 pandemic has led to a dramatic loss of human life worldwide and presents an unprecedented challenge to public health, food systems, and the world of work. The economic and social disruption caused by the pandemic is devastating. In this study, participants were asked about the perceived effects of COVID-19 on families with children with disabilities. The results summarized in Table 37 show that 67.2% of participants reported that the COVID-19 outbreak has had the same effect on their family as on any other family, while 24% reported the outbreak to have had a profound effect on their family.

Table 37: Perceived effects of COVID-19 on families with children with disabilities

Perceived effects	It did not affect us at all	It affected us a little	It affected us moderately	It has had a profound effect on us
To what extent has the COVID-19 outbreak affected your family as a whole?	3(0.5%)	68(8.4%)	542(67.2%)	194(24%)
What is the impact of COVID-19 on the health and upbringing of your children (without disabilities)?	4(0.5%)	61(7.6%)	534(66.2%)	208(25.8%)

In terms of the perceived effects of COVID-19 on the care of children with disabilities, results summarized in Table 38 show that most participants (99.8%) reported that they were not able reach medical or surgical services that their child with disabilities needed. At the time of the study, 17 children with disabilities (2.1%) were living in residential institutions and only one of them was at home at the start of the lockdown period in Rwanda, and was soon returned to the centre for children with disabilities for emergency support.

Table 38: Perceived effects of COVID-19 on the care of children with disabilities

Has the following happened to you due to COVID-19? (You can fill in more than one)	**Yes**		**No**	
	Frequency	**%**	**Frequency**	**%**
I was not able reach medical or surgical services that my child (or children) needed	805	99.8	2	0.2
My child with disabilities who lived in the centre could not come to visit us	0	0	807	100
My child (children) was immediately returned to the care centre for children with disabilities	1	0.1	806	99.9

Table 39 summarizes the responses of participants related to the anticipated effects of COVID-19 on the deinstitutionalization plan for children with disabilities. More than half of participants thought it is possible that COVID-19 may affect the deinstitutionalization process.

Table 39: Perceived effects of COVID-19 on the deinstitutionalization plan for children with disabilities

Perceived effects	**Very likely**	**It is possible**	**Undecided**	**It is impossible**	**Not at all (chances are very low)**
Do you think the effects of COVID-19 will allow Children with disabilities to continue to be raised in residential institutions?	141 (17.5%)	439 (54.4%)	101 (12.5%)	124 (15.4%)	2 (0.2%)
Do you think the impact of COVID-19 can be an obstacle to the acceleration of the deinstitutionalization plan for Children with disabilities?	87 (10.8%)	408 (50.6%)	98 (12.1%)	189 (23.4%)	25 (3.1%)

4. DISCUSSION AND CONCLUSION

The qualitative and quantitative components of this study explored the knowledge towards disability, the attitudes/perceptions held towards children with disabilities, the perceptions towards institutional care and family-based care for children with disabilities, and the perceived barriers of integrating children with disabilities into families and communities. The quantitative survey collected data from parents and caregivers of children with disabilities. In total, 807 caregivers/parents of children with disabilities completed the survey. The qualitative approach included a focus group discussion and individual interviews with professionals. This section aims to discuss, integrate and synthesise the findings. Parents/guardians of children with disabilities and professionals and leaders of residential institutions expressed varying perspectives and outlooks on the lives and provisions for children with disabilities. However, it was made clear that children with disabilities in Rwandan communities and residential institutions still live undignified lives compared to their peers and siblings without disabilities and are hardly guaranteed sustained access to basic services (education, health and appropriate nutrition). This is largely driven by inappropriate attitudes of professionals and community members and inadequate and/or inappropriate basic services and/or provisions for children with disabilities, located in poor proximity to families.

4.1. Knowledge on Disability

Knowledge and understanding on disability constitutes an important source of strength for families when caring for their children (Kandel & Merrick, 2007) and influences decision making around what services and provisions their child accesses (Karangwa, Miles, & Lewis, 2010). Widespread misconceptions about disability, indicated in both the statistical and qualitative data, reveals provisions for children with disabilities is misdirected, and affects children in their early childhood and throughout their lives in community and families.

The opinions of parents, professionals and community revealed the attributes ascribed to children with disabilities, the feelings, emotions, reactions and levels of attachment towards them correlate closely with findings among parents, professionals and community members of the African subregion (Owusu, Enoch, Mprah, & Vampere 2018, Karangwa et al 2010, Karangwa 2018). Accordingly, the dominant attitude and knowledge deficit in many families, communities and institutions about disability also explains the persistent use institutional care for children with disabilities despite their services being inadequate.

The survey findings suggest that, while most parents are aware of the different rights and provisions for children without disabilities, their questions about the needs and services for children with disabilities still go unanswered. It is construable that institutional care emerges as the most preferred option for most Rwandan families because families are ill-informed about disability and there is a lack of adequate information about services for children with disabilities. The main source of information about children with disabilities is from family members and neighbourhoods.

The study proves that having a child with disabilities often traumatises family members, and with limited information on the disability, of the child's needs, and availability of affordable services, their choice of institutional care is not necessarily informed, but instead regarded as the only option for the child to access education, health and/or rehabilitation services. In fact, professionals and parent groups affirmed notable positive changes in parental attitudes, with some community-based support around awareness raising, service provision and family empowerment. They all affirm, with evidence, that by making available some inputs, often through government and civil society agencies, attitudes towards, and services for, children with disabilities have changed for the better at family and community levels.

Related research has demonstrated that parents, who are more aware of the needs of their child and are effective in supporting their child with disabilities, are more likely to be able to cope with caregiving demands, recommending that interventions should be focused on equipping parents with knowledge and means of service provision for their children (Whiting, Nash, Kendall, & Roberts, 2019).

4.2 Attitudes and Perceptions Change towards Children with Disabilities

Among the Rwandan communities surveyed, findings from both the quantitative and qualitative data confirm the high prevalence of negative attitudes towards, and attributes assigned to, children with disabilities (about 80% negative ascriptions for children with disabilities, and about 7% for those without any disabilities). Earlier studies had underlined similar attitudes towards, and attributes assigned to, children with disabilities in Rwandan communities (Karangwa et al., 2010, Karangwa, Ghesquire, Devlieger. 2007). They demonstrated that the frequent use of the prefix "ik" when referring to children with disabilities degrades them to non-human objects and dehumanizes them. It is argued through this study, ten years on, that the persistent use of names such as 'ikiragi, ikimuga, 'ikirema', ikirimarima','ikizeze' is also clear evidence of discriminatory and dehumanizing attitudes towards children with disabilities being present, and an important factor underlying decisions taken by Rwandan families and communities in relation to what support they provide to children with disabilities.

However, despite the negative attitudes, there is also evidence that parents of children with disabilities are becoming more and more successful in developing positive attitudes in their parenting approach. This has been identified as important in the ability of parents to cope (Gupta & Singhal, 2004). Existing evidence indicates that even parents from poor socio-economic contexts have been able to find solutions for their children with disabilities despite the appalling socio-economic conditions they live in (Gupta & Singhal, 2004; Karangwa et al. 2007 & 2010). Civil society organisations working with Rwandan families and communities have continued to report success stories that have contributed towards important changes for children with disabilities (Karangwa, Iyamuremye & Muhindakazi. 2013; Karangwa, and McGeown 2013), moreover with minimal inputs.

The present study has noted with interest that the reported success stories are those that leverage existing community potential to contribute to, or support, community-based strategies or activities that provision for children with disabilities. For example, Umuganda, Ubudehe, Girinka are the culturally and nationally endorsed communal services where members work together for the development of their own community, particularly for the most vulnerable families. The study documents testimonies where community members or organisations have joined hands to support children with disabilities and/or their families, under 'Umuganda' or 'Itsinda ry' ababyeyi' self-help initiatives.

It is worth noting that community members are also important channels through which both attitude change and service provision increases with minimum investment. Interviewed professionals also strongly recommended community-based strategies to be reliable means of combating prejudice, hostility and stigma against children with disabilities, and an important source of social support and access to resources (The African Child Policy Forum, 2011; Njelesani, Hashemi, et al 2018). The study findings also highlight important considerations for Rwanda at a time when the country is investing in the deinstitutionalization of all children and integrating them into family and community-based care.

4.3 Institutional Care and Family-Based Care

Curiously, both the quantitative survey and the qualitative findings highlight controversial feedback from the community respondents. Most parents of children with disabilities were in favour of institutional care (74.7%), although 82.6% of parents agreed to the assertion that they would consider transitioning from institutional care to family and community-based alternatives. It is equally interesting that an overwhelming majority of community members (90.7%) agreed to the assertion *"I would consider raising my child with disabilities in the family"*. Similarly, findings from professionals offered intriguing results, affirming that institutionalisation (50%) and home care (50%) for children with disabilities are equally agreeable to them.

The main reasons cited as to why parents placed their child with disabilities in institutional care included poverty and inadequate health and social services. This was further emphasised by parents of children with severe disabilities, particularly those raising the child alone, who explained they had no other option but to consider institutional care as they were so burdened in caring for their child.

The mindset is further explained by the survey data carried out with professionals. This affirmed that the decision of whether to place a child with disabilities into institutional care is determined by proximity to the institution; affordability of institutional services; the quality of services; awareness levels of the parent; and family links with residential institutions, etc. For example, a single mother of twins with disabilities was stressed and could not afford their schooling, so pursued a placement that she thought would be best for her children.

Related studies on families that opt for placing their children in institutional care (Barriga, Buchanan, Cerimovic, & Sharma, 2015) argue that if parents are provided with provisions that meet the needs of their children, parents eventually favour family-based care, which was confirmed by FGD and professional respondents in this study. The study indicated that as many as 75% of Rwandan parent participants were not aware of the benefits of removing children with disabilities from residential institutions. They believed that institutional care for children with disabilities was appropriate, acceptable, and free of harm. It is thus arguable that, if parents had been equipped with the necessary knowledge and means to support their child in family-based care, and understood the harmful effects of caring for children with disabilities within residential institutions, they are likely to have been more favourable towards home care (Barriga et al., 2015; Johnson, Browne, & Hamilton-Giachritsis, 2006).

In Rwanda, researchers disclosed that children who are placed in residential institutions are likely to be at greater risk of developing externalizing behaviours than their peers in caring families (Nsabimana, Rutembesa, Wilhelm, & Martin-Soelch, 2019). This was affirmed by previous studies, indicating that parent-to-parent involvement in self-help initiatives is quite effective in changing attitudes towards disability and in influencing the ability of parents to cope and address their child's disability (Bray, Carter, Sanders, Blake, & Keegan, 2017; Singer et al., 1999). The present study draws from the existing Rwandan home-grown solutions such as "Inshuti z'Umuryango" "Friends of Families" volunteers, proven successful in supporting the national process of deinstitutionalisation (National Commission for Children, 2012). This is an initiative that can possibly be rolled out to families of children with disabilities. Additionally, Rwanda has registered success with childcare reforms. "Tubarere Mu Muryango", "Let's Raise Children in Families", for example, was a national strategy aimed at prioritising family-based care over institutional care for orphaned children (National Commission for Children, 2012). It is thus understood by the present study that learning from previous experience may pave the way towards reliably planning the deinstitutionalisation for children with disabilities in Rwanda.

4.4 Challenges with Integrating Children with Disabilities into Families and Communities

In this study, there was an overwhelming consensus across the three categories of participants as to what the perceived barriers to successfully integrate children with disabilities into families and communities are. The most common barrier participants cited was inadequate resources to support and provide the required care to children with disabilities in families. Despite outstanding initiatives by the government of Rwanda in providing a supportive environment to people with disabilities, participants in this study highlighted the limited access to opportunities such as education, health and rehabilitation services, assistive aids for mobility, hearing, vision and others.

Accordingly, accessing provisions for the multiple needs of children with disabilities is still a challenge to many parents. This is mainly due to expenses involved, their scarcity, inadequacies, and inappropriateness to cater to the needs of children in communities. More than a half of participants in the quantitative survey reported that their children with disabilities did not attend school. This was mainly because of the family's incapacity to afford tuition fees, and inadequate assistive and disability-friendly facilities in learning/teaching and the general environment. The Njelesani et al's (2018) study affirms that implementation of the existing policies for inclusive education in Rwanda is still facing challenges.

Accordingly, goal one of the five-year Education Sector Strategic Plan (2018/19 to 2023/24) pledges to expand access to education at all levels for all children (Republic of Rwanda 2013: 38), including children with special needs (p. 43) by providing more disability-friendly facilities, training of teachers in related skills and by prioritizing special-needs-related measures. Equally noted was that law No. 01/2007 on 20th January 2007 included the right of Rwandans with disabilities to an education (Articles 11, 12 and 13). This led to Rwanda's ratification of the UN Convention on the Rights of People with Disabilities (CRPD) on the 15th December 2008.

Despite the declared policy orientations however, the ESSP (Republic of Rwanda 2013, 11-25) highlighted the five-year plans for providing schooling to children with disabilities (2013-2018). It affirmed that a 7 to 8 year old children with disabilities is three times less likely to start school at the right age, has an 18% greater chance of repeating a primary school class, and is four times more likely to drop out of school than a child with no disabilities. It stated that for all schools in Rwanda to be disability-friendly is a challenge that will have to be strategically addressed.

Interviewed professionals confirmed this discrepancy between existing policies and what is actually in place. They emphasised that policy provisions and actual education sector facilities in place for children with disabilities are still below the standard requirements. In fact, the professionals recommended that the educational system be reviewed to accommodate the needs of children with disabilities, and the development of inclusive education systems and Community-Based Inclusive Developments (CBID) systems to provide therapy, education and other key services close to families and communities.

Figure 3: Plausible model for Rwanda

In conclusion, while Rwandan policymakers are called upon to develop and reinforce Community-Based Inclusive Developments (CBID) systems for children with disabilities, a lesson from Goldman et al. (2020) is worth heeding. They emphasise that a successful transition to family-based care requires well planned strategic frameworks that strengthen existing community-based initiatives, resources and systems, ensuring that national policies, legislations and regulations are in concurrence with these important resources for children with disabilities welfare and development.

4.5 Recommendations

The present study is of the view that the above WHO-recommended CBID program be underscored as an appropriate approach for deinstitutionalization for Rwanda's children with disabilities. It suggests an all-embracing strategy, in a matrix[2] that brings together education, health, rehabilitation, livelihood, social welfare, and empowerment as an interlinked system of service provision for children with disabilities at family and community levels. However, although it may seem appropriate, it is also expansive and quite a challenge to undertake fully. The study recommends a rather simplified strategy that takes leverage of the existing community-based services to benefit children with disabilities in neighbourhoods. This should consider local families and communities as potential support resources that need to be strengthened to contribute to the positive development of children with disabilities within their families and communities. The approach suggests the development of programs that interlinks two key community-based aspects, repeated in the present study:

1. Empowerment of families and community members and leadership (with awareness and economic means), and
2. Reinforcing available community-based services to include provisions for children with disabilities (education, health, nutrition, social services, etc).

4.5.1 Empowerment of families and community organizations

It was made clear by the present study that the widespread inadequacies in knowledge and attitudes about disability, and needs of children with disabilities, reinforces institutional care. In fact, 80% of the institutional care leaders interviewed, were actually parents of children with disabilities and regarded the occurrence of a child with disabilities in the family as an opportunity to institutionalize others as the most appropriate solution. Residential institutions deprive children with disabilities of family care, affection, and support for a lengthy period of time, privileging provisions of few services to the child.

On the other hand, the present study recommends nurturing organizations of parents with children with disabilities, through which information is disseminated and trainings are conducted to improve knowledge and attitudes towards children with disabilities. This empowers them to change their practices at home and in their entire neighbourhood. Experiences in Rwanda have indicated that with small inputs to self-motivated organizations, tremendous results are made in:

- Sharing positive information and good practice that improves the lives of their children with disabilities, and their own.
- Acquiring knowledge, attitudes, skills, and abilities related to therapy, production of assistive aids for children with disabilities.
- Team up in lucrative ventures to improve their lives, their children's lives, and the lives of the whole family.
- Developing a unified and thus a stronger voice to advocate for their

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[2] https://afri-can.org/cbr-matrix-2/

children with disabilities' needs, rights and entitlements.

- Acting as the vanguards of their respective communities in knowledge dissemination and developing positive attitudes.

Reports from local government and civil society organisations indicate that Rwanda is endowed with several organizations and groups of parents of children with disabilities. Kayonza District reportedly counts more than 14 organisations, while Rutsiro District has about 64 related groups in communities and in ordinary schools. The achievements of each group are varied and depend on inputs from local leadership and other stakeholders. The local strategies and processes in place are key to what the groups can do for their children with disabilities. When the parents of children with disabilities work closely with local leaders (at Mudugudu and sector levels), with volunteer health advisors (Abajyanama b' Ubuzima) and local education guides (Imboni z' Uburezi), quite substantial changes take place that affects the entire community. Either way, the present study considers these as plausible channels for an intervention model that would work for children with disabilities in their families and communities.

4.5.2 Reinforcing community-based services

The study findings revealed needs from professionals and outcries from parents in relation to the basic services available to children with disabilities, especially about education, health, and therapy. They reiterated that these are among the major reasons why parents opt for institutional care, since neighbourhoods where children with disabilities live hardly offer alternative provisions in many communities.

4.5.3 Community-based health and rehabilitation services

Rwanda is known to be endowed with a network of health centres, each of which liaises with volunteer health advisors (Abajyanama b' Ubuzima). These work closely with families in every community. They are known to advise on health basics and administer simple services that have successfully helped pregnant mothers, malaria cases, and others. However, there is no evidence of their implications in supporting children with disabilities in respective communities. In addition, similar structures are known to have been adopted in Kamonyi District to support family organizations and school communities of children with disabilities to provide basic rehabilitation services and develop assistive resources for the children.

This study, therefore, considers both structures as plausible channels for affordable services for children with disabilities because they bring essential health and rehabilitation services to families and/or neighbourhood communities and link expert institutional services (health centres and centres for children with disabilities) with families.

However, community initiatives, parents' organizations, as well as local administration systems are the main prerequisites for the successful development of provisions for children with disabilities within their families and communities. It is through such structures that local experts and community members' trainings could be organized, support services and resources (including volunteer expertise and assistive aids) could be provided to the families of children with disabilities, and follow up monitoring, evaluations and reports be made.

4.5.4 Reforming the roles of residential institutions for children with disabilities

The present study revealed that both parents and professionals strongly value residential institutions, for they have emerged as the only available alternative to offer therapy and education for children with disabilities. Residential institutions reportedly offer expert provisions and relieve parents of the caring burden, so they have time for more productive work.

Based on experiences of CBID projects that have successfully worked in Rwandan communities, the present study suggests reforming the role of residential institutions in a way that their services and resources can be made to serve the wider community rather than being centralised in the centre away from the families of children with disabilities.

Accordingly, it is suggested that residential institutions could be reformed into community outreach resource centres where expert services and resources for children with disabilities are made accessible to their families and communities. It is anticipated that through the strategy, rehabilitation and special educational needs support provisions will be available to the families of children with disabilities, to communities and ordinary schools.

Furthermore, the role of both ordinary schools and special educational institutions for children with disabilities of the same communities could be supported to complement each other in providing educational, therapeutic, and other services. For example, teachers trained in inclusive education and Special Educational Needs Coordinators (SENCO) are known to support children with varying ranges of disabilities by initiating and working through inclusive school clubs. Through such initiatives, and parent associations of children with disabilities, children are organized to support their peers at home and schoolwork. They learn and use braille and Rwandan sign language, for example, with their sensory impaired peers, and report any challenges and abuse they may experience at home and at school.

According to the perspective from parents, four recommendations were proposed. These included:

1) Improving the condition of the home and infrastructure,
2) Improving the medical and educational infrastructure,
3) Alternating home-institutional care, and
4) Increasing support and advocacy to families.

4.5.5 Improving the condition of the home and infrastructure

Parents across the three focus groups agreed that the current condition of home infrastructure for many families is not adequate for a child with disabilities to grow in. They recommended support in improving the conditions. *"Most families with children like this, stay in amanegeka, inaccessible even in a wheelchair…If we could be supported to get a decent place to live in…" (FGD2, Mother). "We live in a tiny room, having to share that same room with a child with a disability is a challenge. Look, we live in very crowded place "utujagari" where a child does not even have a place to even learn to crawl. If support can be made available to improve our home conditions…" (FGD1, Father).*

Access to medical support for children living at home was also identified as one area needing improvement and advocacy. This was strongly voiced among the group of parents who were in the process of receiving their children home. "*If we could have almost the same support as what children have in residential institutions, no single parent would ever want to send his/her child into an institution again. If kids could have access to physio, to wheelchairs, to medical care, that would be helpful to parents" (FGD2, Father).*

Parents who already have children at home have also shared how support to obtain access to health services is still needed. "*When my daughter was back home, I had to go to Ndera for the renewal of her treatment. That was the biggest challenge I faced. But since HHC is getting the treatment for me and sending it over courier, it is better now. We should get regular support for accessing medical care for these children" (FGD3, Mother).*

In addition to advocacy and support, parents recommended improvements to the healthcare service infrastructure, which, according to them, is not adequate for people with disabilities. *"You go to a hospital and find stairs all over the place. There should be provisions to make services more accessible to people with a disability" (FGD2, Father).*

More inclusive schooling opportunities for children with disabilities was also recommended, and mainly discussed among the third group of parents who received their children back. According to parents, when their children were in the institution, they had access to an education, but after deinstitutionalisation most children could not return to school because either their disability did not allow them to be integrated into the regular school, or because there is no accessible specialised school to attend. *"When she was still in the centre, she was attending school and she was the best. She can count from 1 to 10 in English and Kinyarwanda. But since she is here, she stopped going to school and this breaks my heart. Please stay with us, help us to take back our kids to school" (FGD3, Mother).*

Parents whose children are attending regular schools also noted a lack of adequate policy for inclusive education. "*I really think that REB has not yet integrated the idea that some kids with disability can attend regular school. My son is in a regular school. He does not write - he memorises everything. For him to be allowed to sit the national exam, HHC had to strongly advocacy to REB and they sent someone to support him. What will happen to those that are not being supported by HHC? The education policy is not ready for teaching and assessing those children. Then, when they are in the ordinary level, they have limited choices for their advanced level. The only place in Gatagara that receives them does not accept those who are totally dependent. Something must be done for the education of our children" (FGD3, Father).*

4.5.6 Community-based day care as alternatives to residential institutions

Most parents clearly expressed the need for community-based day care, arguing care within families needed to be supplemented. Parents of children with severe disabilities noted that it may not be easy for them to handle the child at home alone whilst contributing to the family welfare at the same time. In their recommendations they suggested an approach whereby homes remain the best alternative for children with disabilities, on the condition that day-care services or related alternative centres remain the source of expert services. They suggest a community-based outreach strategy, deliberately designed to deliver therapeutic, rehabilitation, special needs education or other assistive provisions at family/ community levels.

"At home, they get full care from parents, but they miss an accessible educational and medical support from a specialised centre or an outreach program. My recommendation would be, if possible, children could be given a chance to spend time between their home and community-based day care. They go for a while during the day, they get all the knowledge and benefit from the services, then they have time to be in their family, we give them care, and so on and so forth. I think that could be helpful to children" (FGD1, Mother).

Parents also believed that a limited time away from their homes would be more beneficial to children particularly for families that are faced with extreme poverty and parents who make a living from occasional jobs or subsistence farming. Some children get neglected not because of the parent's choices, but because of the poor conditions. But community day-care centres would give them alternative support.

It is very important to note that these parents highlighted that:

- Currently, educational and medical support is provided by centralised residential institutions that also require children with disabilities to leave their natural family environment.
- They need better access to services to make family-based care in the home possible. Providing these services at home is therefore essential to family-based care. They need respite care which is a common type of specialised care for a short period of rest or relief from the challenges of caring for a child with disabilities.

Parents suggest an approach where facilities, communities and families remain symbiotic service providers to children with disabilities in their homes, similar to strategies prescribed by WHO for under-resourced countries known as Community-Based Inclusive Development (CBID)[2] or Community-Based Rehabilitation (CBR)[3]. Services include education, health, rehabilitation, social welfare, etc. while children with disabilities remain in their families.

4.5.7 Increasing support and advocacy for families

Across the three focus groups, parents highlighted a financial burden associated with caring for a child with disability. Advocacy for improving the socio-economic status of these families was recommended. The following quotes summarize their ideas on increasing access to existing opportunities to benefit families of children with disabilities:

"Raising a child with a disability is an incredible burden to the family. Parents should be supported, waived of some obligations depending on their economic status. In the rural areas, there is the 'girinka' program, if this can benefit a parent, children could get milk. There are a lot of economic projects from donors, parents of children with a disability should be part of the most disadvantaged. We know there is a budget for people with a disability in each district, we don't know what it is used for, we don't benefit from it, us in rural areas we don't even know of these opportunities. These are our children. Sooner or later, they will be living with us. The government should really work hard to support families with such children, same as they do for any other needy citizen" (FGD2, Father).

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[2] https://cbrglobalnetwork.files.wordpress.com/2017/08/final-composite-report-of-2nd-cgn-worldcongress.pdf

[3] https://www.dinf.ne.jp/doc/english/resource/CBID_2015/sheet.html

"Look at this mother (pointing to one of the participants). Her son is 28 years old. They have no source of income. They are very poor. Yet here in our district, there are a lot of plots of land that are freely given to people who are wealthy and able. Can they consider parents like this a priority? Even if it means giving them one square meter. That way, they will have a property on their names, which is good for their self-worth, but also, this can be their source of income or they cultivate it and have something to eat" (FGD3, Mother).

Advocacy was also sought for special consideration of families of children with disabilities when it comes to putting into socio-economic levels "ubudehe" and the subsequent services. This was identified as a cross-cutting challenge that hinders access to medical care as well as access to other social support provided according to these levels. The following quote highlights this:

"I was put in the third category of Ubudehe. This means that my child is also in that category….. I asked if he could be considered apart, they refused saying that a child is considered according to the head of the household, which is a challenge……Why can't they think of considering children with a severe disability on a case-by-case basis?" (FGD3, Father).

4.5.8 Recommendations on improving the lives children with disabilities and community integration

As indicated in Table 40, professionals and leaders of residential institutions recommended strategies to improve the lives of children with disabilities to enable their meaningful integration into the family and community. They suggest wide-ranging levels of interventions, cutting across government, community, and family system.

Table 40: Recommendations on improving the lives of children with disabilities and community integration

Government level	Family & community level
• Develop national strategies for care and education therapy services for children with disabilities. • Develop and make available required human and material resources. • Structure service provision for children with disabilities within the local administrations. • Implement existing policy plans and strategies for children with disabilities. • Increase the budget for the care of children with disabilities. • Equip districts with services to identify, support and provide for children with disabilities. • Develop a particular strategy for changing attitudes and practices especially aimed at professionals (social workers, medical personnel, educators) as the first tool to reach communities and families. • Update data related to children with disabilities disaggregated by key characteristics across the country for scope, services, gaps and needs. • A strategy for engaging stakeholders and demonstrating change for future scale up. • Develop more varied alternative care services dedicated for children with disabilities.	• Sensitize families on the needs and potential of children with disabilities. • Focus more on improving and changing the mindset of parents. • Reinforce community outreach programs. • Involve organizations of PWDs in the sensitization of families and community. • Parents' organizations should include those with children with disabilities. • Establish multidisciplinary teamwork systems of professionals to achieve better results. • Transform existing long-term residential care facilities into community daycare-based services like inclusive schools, community hubs, ECD or day care centers.

After close scrutiny of the local practitioners' views who participated in the study, they recurrently recommend an intertwined response that leverages community-based resources available for children with disabilities to draw on government inputs and strategies as well as from other support agencies. They suggest a community-based strategy that approximates the WHO programs practiced in under-resourced countries including Rwanda[4] in various forms such as Community-Based Rehabilitation (CBR) or "Community-Based Inclusive Development (CBID)[5]. The CBR or CBID matrix[6] is based on community members as the foundational resource, able to activate, mobilise, and organise locally available services and resources, notably education, health, social provisions, and others, to benefit children with disabilities at family and community levels.

4.6 Conclusion

Quite a few lessons have been learnt through the findings in the present study, most of which have been discussed in the previous sections and recommendations.

What seems to be emerging, however, is the view that deinstitutionalization of children with disabilities in favour of reintegration into their families and communities, is a closely-linked strategy that includes:

1. Empowering the families of children with disabilities and community members through knowledge sharing and changing attitudes;
2. Making available necessary resources to children with disabilities and their families and communities; and
3. Fostering or developing economic empowerment ventures for the families of children with disabilities and communities.

The study concludes that with facilitating inputs, and by enabling strategies and processes of the strategy, a lot could be achieved towards the deinstitutionalization of children with disabilities, even with limited resources. However, it must be noted that the accurate identification and understanding of the needs of children with disabilities, and the contexts within which local means and resources are made available, is key to setting and achieving deinstitutionalization goals.

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[4] https://afri-can.org/cbr-matrix-2/

[5] https://afri-can.org/who-guidelines/ /

[6] https://www.dinf.ne.jp/doc/english/resource/CBID_2015/sheet.html

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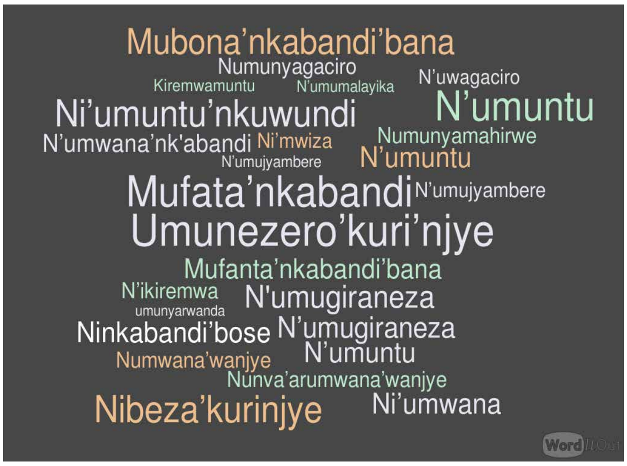
Appendix 1: Words used to describe children with disabilities

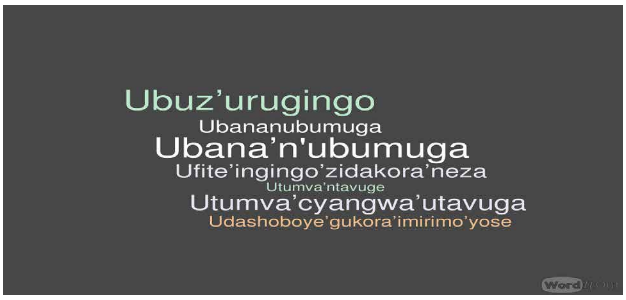
The pictures below show examples of terms people use to describe children with disabilities in the studied communities.

Negative words

Positive words



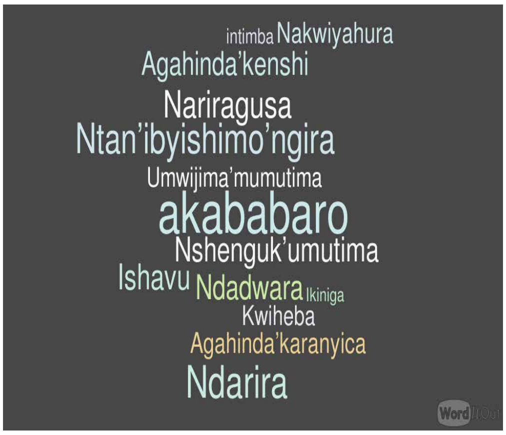
Neutral words

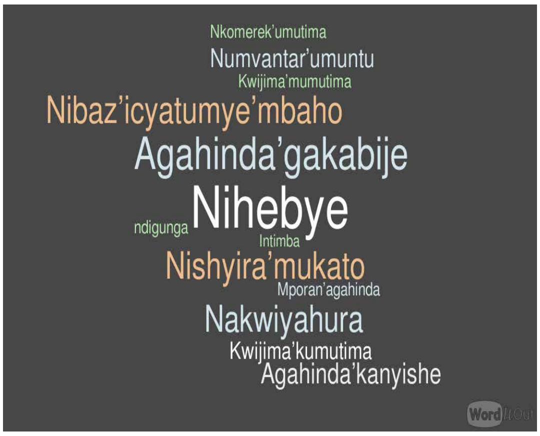


Appendix 2. Feelings frequently experienced by parents of children with disabilities

The pictures below show examples of the feelings parents and caregivers have towards their children with disabilities.

Feelings of sadness and depression

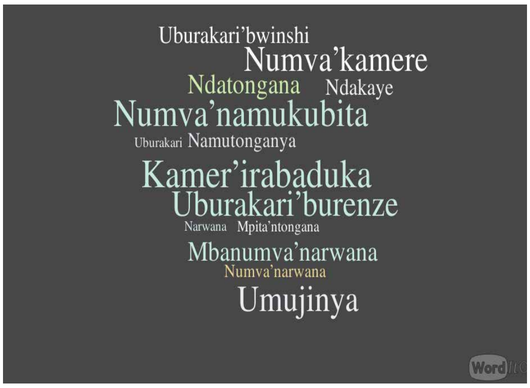


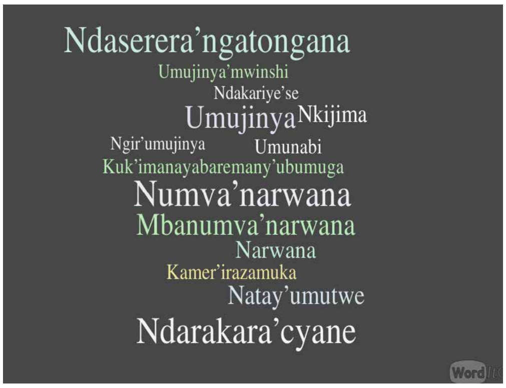


Somatic or physical sensation

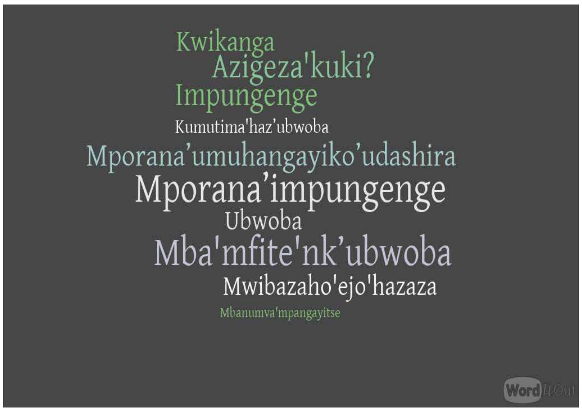
Feelings of being broken/ traumatized

Feelings of anger/ losing control

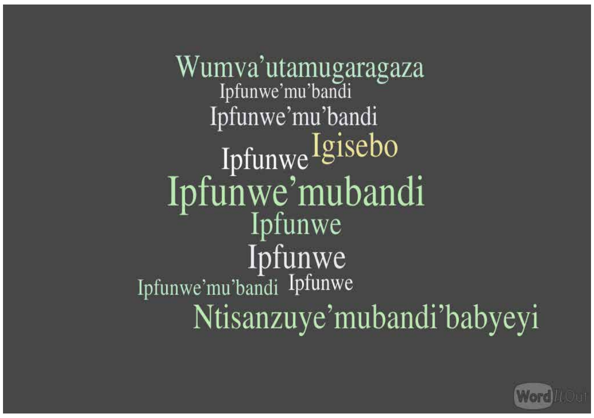




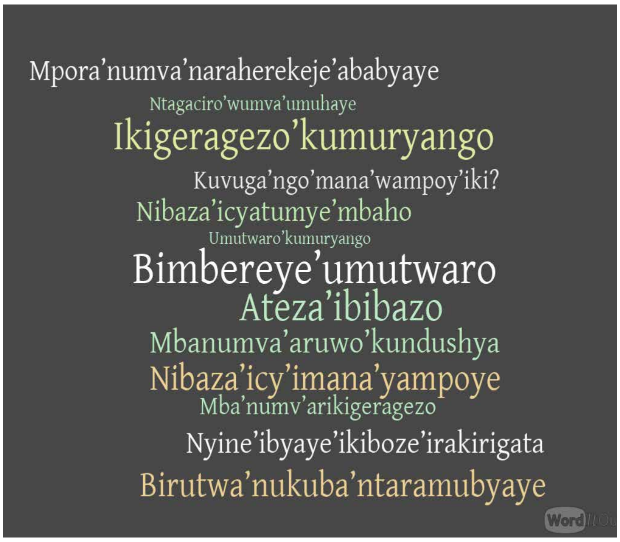
Feelings of fear/anxiety



Feelings of shame

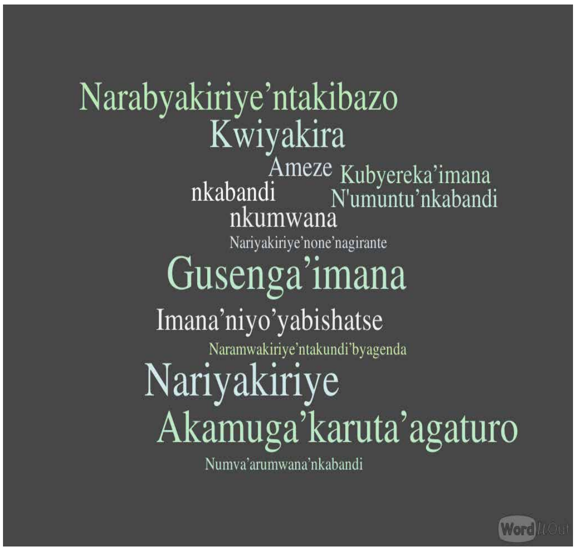


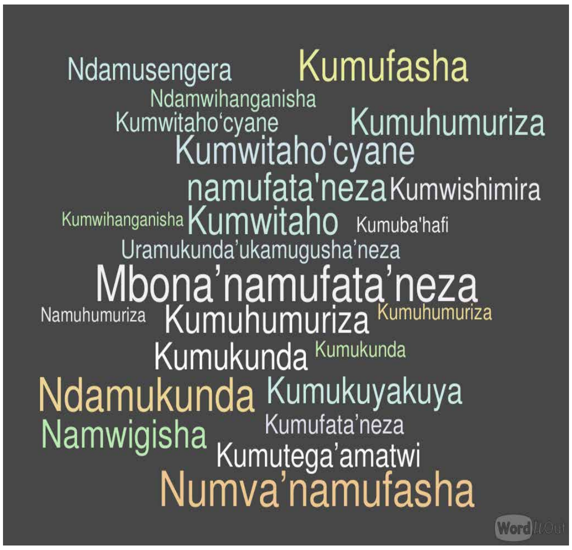
Unbearable pain, unacceptable situation



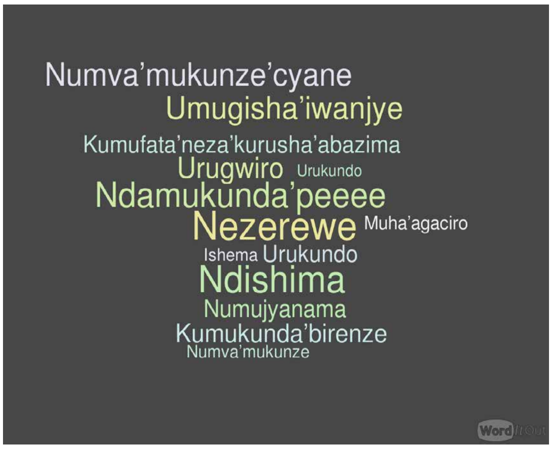
Empathy and compassion

Acceptance, love, positive consideration, willingness to care (wish to provide the maximum possible care)

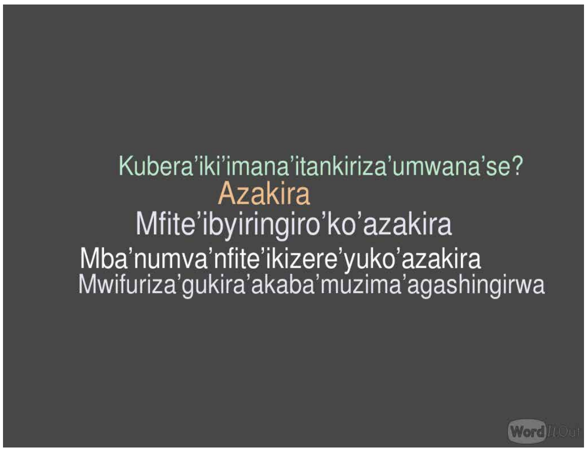




Joy Pride and Happiness



Hope that she/he will be completely cured



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