

Republic of Rwanda



Ministry of Health

Violence Against Children and Youth with Disabilities in Institutional Settings in Rwanda

A Qualitative Study, August 2018

Violence Against Children and Youth with Disabilities in Institutional Settings in Rwanda

A Qualitative Study. Kigali, Rwanda.



Published by
Rwanda Ministry of Health (MoH), 2018



Republic
of Rwanda

unicef 
for every child

IDRC  CRDI

 **RWANDA
BIOMEDICAL
CENTER**
A Healthy People. A Wealthy Nation

The Ministry of Health of Rwanda conducted the Violence Against Children and Youth With Disabilities in Institutional Settings in Rwanda: A Qualitative Study. The financial and technical support was provided by the International Development Research Centre of Canada (IDRC), United Nations Children's Fund (UNICEF) and the US Centers for Disease Control and Prevention (CDC).

Permission to reproduce any part of this publication is required.

Please contact:

Rwanda Ministry of Health
P.O. Box 84 KIGALI, Rwanda
Website: www.moh.gov.rw
Email: info@moh.gov.rw

Table of Contents

Acknowledgements	1
Contributors	2
ABBREVIATIONS AND ACRONYMS	3
SECTION 1. Introduction	4
Background to the study	5
SECTION 2. Key concepts and terms	7
SECTION 3. Infographic	9
SECTION 4. Objectives and methodology	10
4.1 Research objectives	10
4.2 Research Design	10
4.3 Research methods	11
4.4 Study population	11
4.5 Site and participant selection	12
4.6 Sampling	13
4.7 The study team	13
4.8 Ethics	14
Justification for conducting research among children	14
Protection of privacy and confidentiality	14
Reimbursement and incentives	14
Reporting and referral protocol	14
4.9 Challenges and limitations	14
SECTION 5. Children with disabilities in Rwanda	16
5.1 Legislative and policy framework	16
5.2 Overview of children and youth with disabilities in Rwanda	17
5.3 Service provision	18
SECTION 6. Findings of the qualitative study	19
6.1 Context and life in the centres	19
6.2 Perceived benefits of living in residential care	21
6.3 Perceived challenges of living in or attending residential care	23
6.4 Experiences of violence in residential care	24
6.5 Experiences of violence in families and communities	24
6.6 Disclosure and reporting of abuse	29
SECTION 7. Conclusions and recommendations	32
References	34
Annex A. Snapshot of research sites	36
Annex B. Lead institutions and key partners in the study	37
Annex C. Risk assessment	38
Annex D. Informed consent procedures	39
Annex E. Reporting and referral protocol	42
Annex F. Global conventions and regional charters related disability and children’s care in Rwanda	44

Acknowledgements

This qualitative study on violence against children with disabilities was conducted by the Ministry of Health through Rwanda Biomedical Centre under the overall leadership of Prof Jeanine U. Condo.

The study benefitted immensely from the support and collaboration of the Ministry of Health's partner institutions. We are most grateful to the International Development Research Centre, the United Nations Children's Fund and the United States' Centers for Disease Control and Prevention for their financial and technical support. This study would not have been a success without the support and partnership with government institutions especially the Ministry of Gender and Family Promotion, the Ministry of Local Government, the National Commission for Children and the National Council for Persons with Disabilities.

Our sincere appreciation goes to the team of investigators for their hard work, dedication and expertise put into this study, especially to Dr Yvonne Kayiteshonga, the principal investigator, Ms Mechilde Kamukunzi, co-principal investigator and all co-investigators: Aypio Nyandwi from the Ministry of Health, Dr Damascene Iyamuremye, Emmanuel Hakomeza, Nancy Misago and Jeanne D'Arc Dusabeyezu from the Rwanda Biomedical Centre; Germaine Mukabalisa, James Wayo, Josianne Mukamana from the National Commission for Children; Anastasie Nyirabahinde from the Ministry of Gender and Family promotion; Genevieve Uwamariya from UNICEF Rwanda; and Ansley Lemons and Laura Chiang from the US Centers for Disease Control and Prevention.

We would like to especially acknowledge the support provided by the Child Frontiers team who analysed the data and drafted the study report. Special thanks are also extended to UNICEF Rwanda's child protection and social policy team who supported the review and finalization of the report:-Patricia Lim Ah Ken, Sólrún Engilbertsdóttir and Denyse Amahirwe - we appreciate the time you committed to support this study.

We are most grateful to the administrators of the institutions that care for children with disabilities, staff members and caregivers, children and youth with disabilities who accepted to share their lived experiences which form the core substance of this report.

Lastly, we express our gratitude to the team of enumerators and sign language interpreters who interviewed participants to this study.



Dr Diane GASHUMBA
Minister of Health



Contributors

Investigators

Rwanda Ministry of Health / Rwanda Biomedical Centre

Yvonne Kayiteshonga, Principal Investigator

Mecthilde Kamukunzi, Co-Principal Investigator

Alypio Nyandwi

Emmanuel Hakomeza

Jean Damescene Iyamuremye

Jeane D'Arc Dusabeyezu

Nancy Misago

UNICEF Rwanda

Genevieve Uwamariya

Sólrun Engilbertsdóttir

National Council of Persons with Disabilities

Marcel Nkurayija

Rwanda Ministry of Gender and Family Promotion / National Commission for Children

Germaine Mukabalisa

James Wayo

Josianne Mukamana

Anastasie Nyirabahinde

United States Centers for Disease Control and Prevention

Ansley Lemons

Laura Chiang

Data collection

Habumuremyi Serge

Irizabimbuto Fidele

Manzi Camille

Nashimwe Dorcas

Niyomwungeri Eric

Nyiransengiyumva Judith

Twizerimana Dalila

Uwiragiye Kellya

Data analysis and report writing

Child Frontiers

Gillian Mann

Emma de Vise Lewis

Internal reviewers

Alypio Nyamdwi

Anastasie Nyirabahinde

Damascene Iyamuremye

Denyse Amahirwe

Genevieve Uwamariya

Patricia Lim Ah Ken

ABBREVIATIONS AND ACRONYMS

ACPF	African Child Policy Forum
BCN	Better Care Network
CDC	Centers for Disease Control and Prevention
CYWD	Children and Youth with Disabilities
DHS	Demographic Health Survey
FGD	Focus Group Discussion
GBV	Gender-based Violence
GSHS	Global School-Based Student Health Survey
IDI	In-depth Interview
IRB	Institutional Review Board
KII	Key Informant Interview
MICS	Multiple Indicator Cluster Survey
MOH	Ministry of Health (Rwanda)
NCPD	National Council of Persons with Disabilities
PID	Participant Identification Number
PWD	Persons with Disabilities
RBC	Rwanda Biomedical Centre
TDH	Terre des Hommes
TMM	Tubarerere Mu Muryango
UN	United Nations
UNICEF	United Nations Children's Fund
VACYS	Violence against Children and Youth Survey
WHO	World Health Organization

SECTION 1

Introduction

Ending violence against children is a global priority clearly articulated in the 2030 Agenda for Sustainable Development and its 17 Sustainable Development Goals (SDGs). All boys and girls are vulnerable to violence, but those with disabilities are especially at risk.¹ The probability of being beaten, bullied and excluded at home, in school and in the community are greater for children in these circumstances, as are the risks of being sexually abused.² High levels of stigma against those with disabilities means that their experiences are often not understood or acknowledged, thus increasing their vulnerability to violence. In such circumstances, avoiding, fleeing and fighting back may be impossible for some children. Reporting violence can also be extremely challenging for those who rely on others for assistance with mobility, communication and other essential capabilities. Moreover, in those rare instances where children do report, prejudice against those with disabilities can mean that boys' and girls' accounts are not taken seriously.³

Understandings and definitions of disability vary by context, but it is estimated that persons with disabilities comprise an estimated 15 per cent of the world population.⁴ Significant numbers of children – up to 150 million, according to the World Health Organization (WHO) and the World Bank – have disabilities of a physical, cognitive and/or sensory nature.⁵ The heightened risk of suffering violence faced by these children is attributable more to the attitudes and approaches of those around them than to their disability per se.⁶ Marginalization in their homes and communities and nonexistent or inadequately enforced legal protection are especially common in resource-constrained settings, where disability has significant implications for the livelihoods and lives of parents and other family members.⁷ Limited support for families, high levels of poverty and inaccessible health, education and social services often augment the emotional, physical, financial and social challenges faced by families and perpetuate negative stigmas. The result is a vicious cycle that increasingly places children with disabilities at ever-greater risk of violence in the home, at school and in the wider community.⁸ Research suggests that 70 per cent of children with disabilities in the developing world have experienced some form of abuse,⁹ and that they are 1.7 times more likely to experience violence than their non-disabled peers.¹⁰

¹ UNICEF 2005.

² Ibid 2005.

³ ACPF 2011.

⁴ WHO & World Bank 2011.

⁵ WHO & World Bank 2011; BCN & EveryChild 2012.

⁶ United Nations 2006.

⁷ BCN & EveryChild 2012.

⁸ Winters et al. 2017.

⁹ Stopler 2007; Njelesani et al. 2018.

¹⁰ UNICEF 2005; also see Ellery et al. 2011; Rosenthal 2009.

In an effort to access much-needed care, protection and services, families in many contexts place children with disabilities in institutional care, either in disability-related residential schools, institutions or hospitals, or in the criminal justice system.¹¹ Often those placed in institutions reside there for the duration of childhood and sometimes their entire lives.

Institutionalization is understood to have harmful physical and psychological effects on children.¹² Globally, studies on the experiences of children and youth with disabilities in institutions have highlighted at least three significant concerns with institutional care and their corresponding impacts.¹³ The first is violence victimization through routine subjection to physical, sexual, verbal and emotional / psychological abuse by staff, visitors and fellow residents. The second is life-threatening neglect: boys and girls with disabilities are often kept in inhumane environments where their basic needs are not met. In many institutions, infants, children and adolescents with disabilities are kept in overcrowded wards. These children have little or no physical contact with caretakers, lying for hours or days on unchanged urine-soaked mattresses and suffering from undernourishment and malnutrition. The third concern is the understaffing of institutions. Children are not only left unattended for long periods of time during the day, but overnight entire wards are often unattended or padlocked with only a skeletal night shift to oversee facilities with hundreds of children. In such contexts, physical and sexual abuse can be widespread. Moreover, because of the demanding nature of the care-work, which is also low-paid and lacks social status, administrators often resort to employing unskilled, overworked staff. Among the regularly reported issues that arise with such staff are a lack of understanding of children's capabilities; targeting of children for violence; lack of facilities specifically designed for children; lack of heat and food; and a lack of oversight / monitoring.

In addition, children in institutions may hesitate to identify their abusers for the same reasons that children are afraid to identify abusers in their household or community. They fear physical, sexual, or psychological reprisal; they fear loss of attention or affection from individuals on whom they have come to depend; they fear they will not be believed; and they fear that they will be blamed or otherwise embarrassed or humiliated.¹⁴

Background to the study

According to the Rwanda Fourth Population and Housing Census, children and youth with disabilities aged 10-24 represented 2.7 per cent of the total population in 2012.¹⁵ This figure comprised those with impairments related to mobility (38 per cent), learning (26 per cent), vision (13 per cent), hearing (12 per cent) and other issues such as epilepsy (12 per cent). This is substantially lower than the WHO and World Bank estimate (2011) that 15 per cent of the global population have disabilities. Definitions of disability are not universal and depend on the severity of impairments: whether or not an individual is defined as being disabled is thus both a medical and a social construction. Moreover, determinations of population size are reliant on people's willingness to acknowledge that they have a child with disabilities.¹⁶ It is therefore expected that the actual number of children and youth with disabilities in Rwanda is significantly higher than reported.

The negative consequences of institutional care have been highly influential in the development of the care reform agenda in Rwanda. But, despite government commitment to close childcare institutions across the country and place all children in family-based care, the de-institutionalization of boys and girls with disabilities has yet to take place. The 2016 National Assessment of Centres Caring for Children with Disabilities found that the numbers of children with disabilities attending or residing in institutions has actually been increasing since 2013.¹⁷ In 2016, the official count in the 49 centres across the country was 4,349 children.¹⁸ However, because almost a third of facilities were unable to provide accurate documentation, this figure is understood to be an underestimate.¹⁹

¹¹ UNICEF 2005.

¹² For a summary of the evidence, see, for example, Browne et al. 2009; Williamson & Greenberg 2010; UNICEF 2010.

¹³ These findings are derived from a systematic review and a meta-analysis of observational studies on the prevalence and risk of violence against children with disabilities (Jones et al. 2012).

¹⁴ Ibid 2012.

¹⁵ National Institute of Statistics Rwanda 2012. High levels of stigma associated with disability in Rwanda, as elsewhere, suggest that these figures are an underestimate.

¹⁶ United Nations 2011.

¹⁷ National Council of Persons with Disabilities & National Commission for Children 2016: 4.

¹⁸ Ibid.

¹⁹ Ibid.

Persons with disabilities are an understudied population in Rwanda, and children and youth with disabilities (CYWD) have received little attention. With the exception of the National Assessment conducted in 2016, only a handful of reports are in the public domain. These tend to be small-scale scoping exercises undertaken in recent years; most are general in nature and have tended to focus on education.²⁰ To date, there have been no studies published that specifically examine the relationship between children and youth with disabilities and violence in institutional care in Rwanda (and hardly any elsewhere),²¹ despite the risks they face as a result of institutionalization and the fact that they represent the largest group of children believed to be at highest risk of violence.

This qualitative study fills this important gap. It was designed to better understand the patterns and dynamics of violence experienced by this vulnerable and frequently overlooked group of children and youth. Its findings are intended to accompany the prevalence data derived from the 2015 national violence against children and youth survey (VACYS) in order to ensure that their reality is given adequate attention and consideration in the development of a more comprehensive plan to tackle violence against all children and youth in Rwanda.

²⁰ Hope and Homes for Children 2012; <https://chanceforchildhood.org/what-we-do/eee-project/>; baseline data for the National Assessment of Centres Caring for Children were derived from a National Council for Persons with Disabilities field visits conducted March-May 2012.

²¹ Jones et al. 2012.



SECTION 2

Key concepts and terms

A number of concepts and terms were used in this study and are referred to throughout this report.

Child:

Any person under the age of 18 (UN 1989).

Childhood:

Someone's lifetime before the age of 18 (UN 1989).

Young person / young woman / young man / youth:

Someone aged 18-24 years (Rwanda MoH et al. 2016).

Persons with disability

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (UNCRPD 2006).

Exclusion

The process that prevents certain people or groups from fulfilling their rights (Plan International 2016). This process involves complex social, cultural, economic, spatial and environmental factors and dynamics that create inequality in people's access to and control over opportunities and resources.

Physical violence:

The intentional use of physical force with the potential to cause death, disability, injury or harm. The term includes punching, kicking, whipping, beating with an object, choking, suffocating, attempted drowning, intentional burning, using or threatening with a knife, gun or other weapon (Rwanda MoH et al. 2016).

Mental or emotional violence:

A pattern of verbal behaviour over time or an isolated incident that is not developmentally appropriate and supportive and that has a high probability of damaging a child's mental health, or his/her physical, mental, spiritual, moral or social development. In this study, emotional violence includes the psychological maltreatment of children including conveying to children that they are worthless, unloved or unwanted; threatening, intentionally ignoring children or showing favouritism; insults, name-calling or humiliation and exposing children to domestic violence (Rwanda MoH et al. 2016).

Sexual violence:

This term includes all forms of sexual abuse and sexual exploitation and encompasses a range of acts, including completed non-consensual sex acts (i.e. rape), attempted non-consensual sex acts, abusive sexual contact (i.e. unwanted touching), and non-contact sexual abuse (e.g. threatened sexual violence, exhibitionism, verbal sexual harassment). Sexual violence also includes the inducement or coercion of a child to engage in any unlawful or psychologically harmful sexual activity; the exploitative use of children in prostitution or other unlawful sexual practices; and the exploitative use of children in pornographic performances and materials. In this study, reference is made to the following four types of sexual abuse and exploitation (Rwanda MoH et al. 2016).

Unwanted sexual touching: Touching in a sexual way without one's permission. It includes fondling, pinching, grabbing, or touching on or around a person's sexual body parts. It does not include trying or forcing to have sex.

Unwanted attempted sex: An attempt to make a person have sex against their will without success.

Physically forced sex: Making someone have sex against their will by physical force.

Pressured sex: Making someone have sex against their will through harassment, threats or tricks.

Neglect:

deliberate failure to meet a child's physical and emotional needs, to protect them from danger or to register their birth when those responsible for their care have the means, knowledge and access to services to do so (UN 2010).

Alternative care:

The formal and informal care of children outside of parental care. Children outside of parental care are children not in the overnight care of at least one of their parents. Forms of alternative care including kinship care, residential care, and foster care (UN 2010).

Residential care:

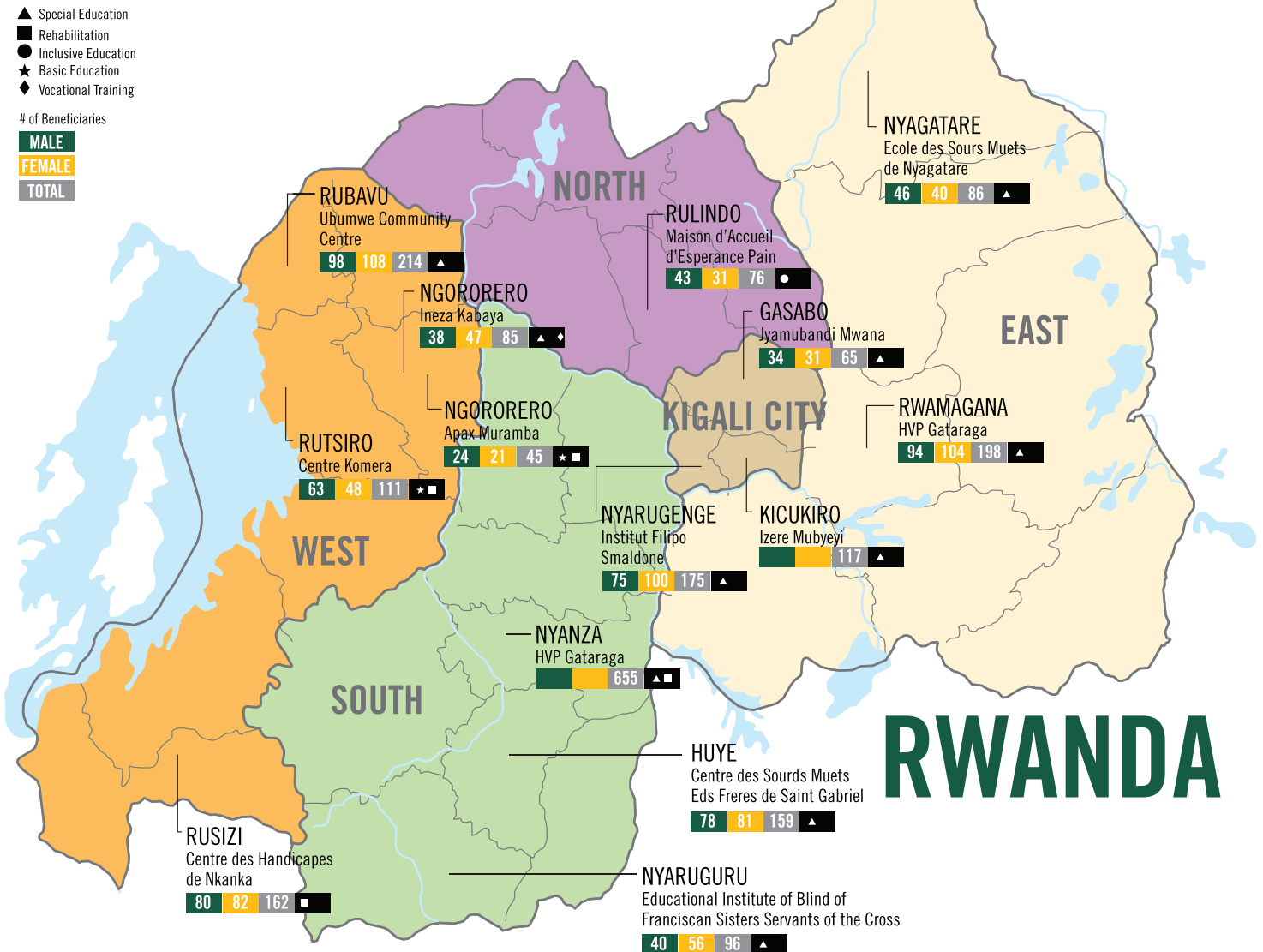
Care provided in any non-family based group setting. A distinction is often made between different forms of residential care:

Institutional care: large-scale facilities where children are cared for in large groups, usually involving shift-systems, a common set of rules, children sleeping in dormitories, and isolation from wider communities.

Small group homes: Children cared for in small groups, usually with one or two consistent carers, in especially designed and designated facilities (BCN & EveryChild 2011).

SECTION 3

Location of Research Sites



SECTION 4



Objectives and methodology

This section outlines the objectives of the study and describes the methodology designed to ensure the successful achievement of these objectives.

4.1 Research objectives



This qualitative investigation was designed to inform policy makers, health, education and social welfare professionals, families and communities about the scope and nature of violence committed against children and youth with disabilities in Rwanda.

Objective 1: Explore the context in which physical, sexual and emotional / psychological violence and neglect occurs against children and youth with disabilities in institutions and attending daycare centres.

- a. Identify the perpetrators of physical, sexual and emotional / psychological violence, and the conditions under which violence occurs.
- b. Describe the role of the institution and caregivers in the context of physical, sexual and emotional / psychological violence against children and youth.
- c. Identify the risk and protective factors contributing to the violence against children and youth with disabilities.

Objective 2: Assess the knowledge and utilization of medical, psychosocial, legal and protective services available for children and youth with disabilities who have experienced sexual, emotional/ psychological and physical violence.

Objective 3: Identify areas for further research regarding violence against children and youth with disabilities.

4.2 Research Design



This was a multi-sited, descriptive study that involved qualitative research. It was designed to accompany the national household survey on violence against children and youth (VACYS) conducted in 2016. Children and youth with disabilities were not included in that survey – this study was thus seen as a means of providing relevant, up-to-date insights into the experiences and perspectives of this population. This information is essential to the national project of understanding the complexities of violence against all children and youth, and to the refinement and development of efforts to prevent and address its impacts.

4.3 Research methods



This study employed three main methods of data collection:

Key informant interviews (KIIs): KIIs were conducted at each of the participating institutions with either an administrator or a caregiver working there. The interviews lasted approximately 30-45 minutes and followed a specific script. Respondents were told that the study aimed to learn about the life experiences of CYWD. They were asked to describe the children and young people who attend their institution, including demographics, orphan status, parental involvement, socio-economic status and education, and to provide any other relevant information. They were also asked to suggest how the situation of the CYWD could be improved.

In order to protect participants from potential retaliation, the interviewer did not reveal to the respondents that the study was focusing on the experiences of violence among CYWD. No personally identifying information was collected, and the names of participating institutions have been kept confidential to ensure that individual responses cannot be traced.

In-depth interviews (IDIs): IDIs were conducted with children and youth with disabilities in institutional care. IDIs were used to capture the range of violence experienced by CYWD and the context under which violence has been and is experienced.

An interview guide for male and female respondents was used to ensure the topics of interest were thoroughly discussed. Specifically, participants were asked to describe how they became involved with the institution from which they receive services; how they perceived their lives in comparison to other children and youth in their home community; their daily interactions; their home life and interactions with their family and community; experiences with violence and neglect in their home, community and at the institution; their ability to seek help or disclose experiences with violence; and any risk and protective factors that might influence their experience with violence, such as their sense of safety, friendships, prior pregnancies or orphan status.

IDIs took approximately 1–2 hours to complete and were audio-recorded, with participants' permission. Detailed notes were taken during interviews with participants who did not wish to be recorded. All interviews were conducted in a private location at the institution. Participants provided oral informed consent prior to the interview. Interviews were conducted in Kinyarwanda or English, or in the sign language used in Rwanda for participants with a speech or hearing disability.

There is as yet no standardized national sign language in Rwanda (though the differences in sign languages used across the country are minimal). However, to fully ensure comprehension among this respondent group, a sign language interpreter from the Rwanda Deaf Association assisted in those cases where the respondent did not know standard Rwandan sign language (this information was obtained in the screening process). In these cases, two interviewers proficient in sign language worked together to simultaneously interview and translate verbally the participant's responses for the tape recorder.

Focus group discussions (FGDs): FGDs were conducted with institutional staff, such as nurses, counsellors, psychologists, social workers and teachers. The FGDs aimed to understand group norms around disciplinary practices, discover the challenges faced by these staff when working with CYWD, gather evidence of peer-to-peer violence among CYWD, and understand knowledge, attitudes and beliefs related to violence against CYWD. FGDs did not take place with institutional staff from any of the institutions where CYWD were being interviewed.

4.4 Study population



The primary population for this study included male and female children and youth with disabilities aged 13–24. Staff from institutions that provide services to these children were also interviewed, either in key informant interviews (for institution administrators), or focus group discussions (for teachers and other caregivers such as nurses, counsellors and psychologists).

Criteria for inclusion are outlined in Section 4.5.

4.5 Site and participant selection



Site selection: Initially, institution administrators were contacted by the Ministry of Health to discuss the study and to determine whether they were willing to allow investigators to recruit participants from their institution. Study investigators then assigned the institution as either a site to recruit CYWD or caregiver staff, based on information about the number of CYWD it services and the type and number of staff working there. At each facility, interviews were held either with children and youth with disabilities or with caregiver staff. This approach was designed to prevent a victim and their perpetrator being interviewed at the same site, which might risk the safety and privacy of the participants.

Institution administrators or other staff were asked to take part in a key informant interview to learn more about their institution and the population they serve. This interview covered basic information about the type of services and facilities provided by the institution. Administrators were not told that participants would be asked about any physical, sexual, or emotional / psychological violence they may have experienced or witnessed. This information was withheld in order to protect the safety and confidentiality of the study participants.

Participant listing: Purposive sampling was used to identify and recruit study participants into the study. For institutions selected as a CYWD site, administrators were asked to create a list of all eligible CYWD based on the following criteria:

- Male or female aged 13–24.
- Currently living at or attending a participating survey site.
- Having one of the following disabilities:
 - Physical, including mobility impairments.
 - Visual, provided the respondent would be able to communicate verbally with the interviewer(s).
 - Intellectual, provided the respondent had been assessed by an institution caregiver as having a low to mid intellectual disability. (This would be confirmed by the respondent passing a standardized cognitive assessment administered by the interviewer.)
 - Hearing or speech, provided the respondent was able to communicate using a sign language understood and used by the interviewer. (Children and youth who did not use sign language were excluded from the study, as it would not have been possible to effectively communicate with them.)
- Was not from the same institute as any staff / caregiver participant.
- Was fluent in Kinyarwanda or English.
- Provided verbal consent to participate in the study.

Respondents with more than one of the above disabilities could be included if they were still able to provide informed consent and were able to understand and respond to the interview questions.

Based on the number of eligible males and females, study staff informed administrators whether male or female CYWD were to be recruited from their institution. Only males or females were recruited from each site - there were no sites where both males and females were recruited. This rule was in place to prevent the likelihood that both a victim and their perpetrator would be interviewed at the same site, thereby risking the safety and privacy of the participant.

For institutions selected as caregiver sites, administrators were asked to compile a list of eligible caregiver staff based on the following criteria:

- Staff member was a teacher, social worker, counsellor, psychologist or other related caregiver at the institution.
- Staff member had been in regular contact with children and youth with disability at their institution for at least 6 months at the time of interview.
- Was not from the same institute as any child or youth participant.
- Was fluent in Kinyarwanda or English.
- Provided written consent to participate in the study focus group discussion.

Participant selection: For potential CYWD participants aged 13-17, a study interviewer first contacted the parent / primary guardian and informed them of the aim and objectives of the study. The interviewer read a standard script to ensure all parents were given the same information. Parents were not told that participants would be asked about

any physical, sexual, or emotional / psychological violence they may have experienced (in order to ensure the safety of the participant in cases where a parent or guardian had been or was a perpetrator of violence). The interviewer then sought verbal consent from the parent for their child to take part in the survey. Once this consent was obtained, a study interviewer sought informed verbal assent from the child participant.

When approaching potential CYWD participants aged 18-24, a study interviewer first informed each individual of the aim of the study and then sought their informed verbal consent.

For institution caregivers, the study interviewer first informed the respondent of the aim of the study and then sought informed written consent.

Only respondents providing informed consent were able to participate in the study. Full details of the informed consent process are outlined in Annex D.

Participant screening log: Study interviewers kept a log of the screening process for all parents / primary guardians of eligible CYWD, eligible CYWD respondents, and eligible staff caregivers and administrators who were approached to participate in the study and chose to decline. The log recorded the respondent's age, sex, disability (if applicable) and reason for not participating. No identifying information was recorded. It is hoped that these screening logs will assist future researchers to identify barriers to participation and to ensure research can be as inclusive as possible.

4.6 Sampling

In total, 39 individual interviews were held with children and youth aged 13-24 at 12 centres across the country. A further 12 interviews were held with senior staff working in centres and 29 caregivers were consulted through focus group discussions. The details of the sample are shown in the following table.

Table 1. Details of the study sample

Category	Number
Individual interviews with children and youth aged 13-24	39 (20 female, 19 male)
Individual interviews with children aged 13-17	17 (8 female, 9 male)
Individual interviews with youth aged 18-24	22 (10 female, 12 male)
Individual interviews with children and youth who are blind	6 (1 female, 5 male)
Individual interviews with children and youth who are deaf	12 (5 female, 7 male)
Individual interviews with children and youth who have physical disabilities	16 (11 female, 5 male)
Individual interviews with children and youth who have epilepsy	3 (3 female)
Individual interviews with children and youth with intellectual disabilities	4 (2 male, 2 female)
Centres where interviews took place	12
Key informant interviews held with senior staff (directors, head teachers and administrators)	12
FGDs conducted with caregiver staff	4

4.7 The study team

Interviewers were Rwandan males and females fluent in Kinyarwanda and English. They were sensitive to the needs of children and youth or had some experience working with boys and girls with disabilities. All were recruited by the Ministry of Health, with guidance from the VACYS Steering Committee; they were not affiliated with or employed by any of the centres where the data were collected. Before data collection commenced, all interviewers took part in a training workshop that elaborated on the study and its objectives; methodology and methods; mechanisms for data capturing; and behavioural research ethics, including child protection, violence against children and sensitivities related to disabilities. Four of the interviewers are fluent in sign language.

4.8 Ethics



Conducting a study of this kind requires that ethical issues be considered thoughtfully and in detail in advance of data collection. Ethics training was an important component of the preparatory workshop mentioned above. The WHO Ethical and Safety Recommendations guided these sessions and the design of the risk assessment and informed consent processes.²² These processes are outlined in detail in Annexes C and D.

Justification for conducting research among children

In order to conduct this study, it was important to select a population that closely approximated to the age of children and young people under scrutiny. A precedent for this approach has been set in many parts of the world, where adolescents and pre-adolescents have been interviewed and engaged in discussions on the topic of violence victimization. For example, the national Violence Against Children Surveys previously implemented by CDC and in-country partners in Swaziland, Tanzania, Kenya, Zimbabwe, Haiti, Cambodia, Laos, Zambia, Nigeria and Indonesia included participants aged 13-24. The Global School-Based Student Health Survey (GSHS), which has been conducted in over 50 countries around the world, asks questions about violence to children as young as 13. The Health Behavior in School-aged Children (HBSC) survey, initiated in 1982, focuses on pre-adolescents from the age 11 onwards. The HBSC, which has been conducted in over 40 countries, asks questions on sexual behaviour and violence. In the United States, there have also been studies in which children as young as 10 years of age have been interviewed about sexual violence; the data from these studies have been extremely effective in mobilizing key entities to take action to prevent violence against children.

Protection of privacy and confidentiality

Throughout the study, procedures were put in place to protect participants' privacy and to keep their data confidential. All interviews were conducted in private locations, unless the participant requested that another area be used. Participants' names were not recorded on any data collection instrument. While participants' first names were used during the interviews, to facilitate rapport, individual names were not recorded in the transcript of the interview. Each participant was assigned a unique participant identification number (PID) for use on all data collection materials, notes and transcripts. The institution from which the participant was recruited was included in their PID in order to identify the participant by group – e.g. "I1" for Institution 1 or "I2" for Institution 2, allowing the participant groups to be known during analysis. The electronic document held by the Ministry of Health that links participant names (only for those who gave consent to be referred for services) with their PID is password-protected on a password-protected computer. Any printed documents linking interviewees' names with their PID are kept in separate locked file cabinets from those containing data. No names nor PIDs are used in this report and will not be cited in any other publication.

Reimbursement and incentives

There were no costs to participants for their study participation. However, light refreshments were provided to CYWD participants either before or after their interviews and to staff before or after focus group discussions.

For parents or guardians who travelled to the institution to provide consent for their child, the study reimbursed reasonable transport costs. It also reimbursed transport costs incurred by institution staff traveling to the FGD location.

Reporting and referral protocol

In the event that participants recalled frightening, humiliating or painful experiences, the study protocol was designed to assist those participants who needed and wanted help through direct service referrals. The response plan guidance document created by the VACYS Technical Committee was adapted for use in this qualitative study. The basic tenets of the response plan are detailed in Annex E and were refined as a final Study Response Plan prior to piloting and data collection.

4.9 Challenges and limitations



Gathering qualitative information about violence is a challenging undertaking, especially when seeking the insights of children and young people whose views and experiences have rarely been solicited and acknowledged. A detailed risk register was developed before collecting primary data. Although mitigation strategies were also outlined, a number of challenges were nevertheless confronted.

²² World Health Organization 2001.

Methodology: The questionnaires did not adequately capture information on the main concerns around institutional violence and neglect. Questions in the in-depth interviews and key informant interviews that focused on violence and abuse were primarily framed within community and family settings with one question (in the focus group interviews) focused on abuse of children under care by employees of an institution; more probing in FGDS was required in order to gain more understanding on violence in institutional care.

Some children and young people appeared incapable of responding to the questions asked and had difficulty communicating with interviewers. The prescribed practice is to administer a cognitive test in advance of conducting an interview to ensure the capacity of the respondent to engage.

Respondent groups: A large number of children and youth interviewed had either hearing or visual impairments (18 in all) or a physical disability (16). There were four children and youth who had an intellectual disability and a further three who had epilepsy. This imbalance in the representation of people with different disabilities in the study sample may have influenced the findings because the experiences and vulnerabilities of children and youth with intellectual disabilities, for example, are likely to be different from those with hearing or visual impairments. Participants in the FGDs, for example, asserted that it was common for children and youth with intellectual disabilities to be considered worthless and to be treated far worse than those with other disabilities.

Parents, siblings and community members such as teachers and health workers were not interviewed. In many cases, these perspectives would have provided important and much-needed insights. Engaging with these groups would also have enabled more effective triangulation of the findings generated from interactions with children and centre staff.

Data quality and transcription: In general, the quality of the data is uneven and interview transcripts often contain insufficient information. From the transcripts, it appears that interviewers rarely probed when further details would have been helpful or when contradictory information emerged. Sometimes questions were skipped, with no explanation provided. It is not clear that the data collection tools used (either the methods themselves or their constituent questions) were the most effective in terms of building trust between interviewers and respondents; disclosure on sensitive matters (such as children's sex lives and experiences of sexual abuse) requires a strong rapport between interviewer and interviewee in all circumstances, especially when interacting with children and youth.

SECTION 5

Children with disabilities in Rwanda

5.1 Legislative and policy framework

Parental and state responsibilities to children with disabilities in Rwanda are set out in a number of national laws, policies and strategies. Guidance for these documents is derived from a number of international conventions and standards, including the United Nations Guidelines on Alternative Care and the United Nations Convention on the Rights of the Child (the latter was ratified by the Government of Rwanda in September 1990). Annex G lists the relevant articles in these and other international conventions, plus guidance related to children with disabilities living in or attending institutional care in Rwanda.

Numerous national laws in Rwanda reflect the principles outlined in these international and regional agreements. Paramount among these is the Law n° 054 on the Protection of the Child (ratified in December 2011), which outlines the standards governing the care of children as they grow up, including what should happen or be put in place in specific circumstances. In particular, it delineates the child's right to know his or her parents, to reside with them and to receive care and protection from them whenever possible. Where temporary or alternative care is required, a child is entitled to family-based care or placement in an appropriate childcare institution. The law acknowledges the need for some children with disabilities to receive care and treatment in an institutional setting. Such care should be provided on a short-term basis. Longer periods in an institution should only be used as a last resort, only if treatment or education and / or vocational training is provided, and when it is established that institutional care is in the best interest of the child.

The Law relating to the Protection of Persons with Disabilities in General (2007) also recognizes the right of children with disabilities to live in a family and to be treated equally with others. It emphasizes the importance of children's participation in family life and outlines the role that centres caring for children with disabilities should play, not only in securing the health and wellbeing of children, but also in supporting their integration into family, school and community life. This law mandates the requirement of the state to monitor and support the centres that serve the needs of children with disabilities.

The National Education Policy (2005) mandates compulsory, free primary education accessible to all children. The Constitution asserts that all persons with disabilities have a right to an education that accommodates their disability.

The Integrated Child Rights Policy (adopted by Cabinet in August 2011) reflects the view that all children, notwithstanding any disability, have the right to grow up in a family environment. To accomplish this goal, children residing in institutions should be reunited with family or placed in alternative family-based care. The process for doing so is operationalized in the National Strategy for Child Care Reform, endorsed by the Cabinet in 2012, through the

National Commission for Children's Tubarerere Mu Muryango (TMM, Let's Raise Children in Families) programme. TMM is responsible for the reintegration of children from institutions and other forms of residential care. Deinstitutionalization is now underway among the general population of children living in residential facilities. But placing these children in alternative care has proved challenging because many families are unwilling, for financial, social and personal reasons, to take on the care of a child with disabilities. TMM has yet to be undertaken with boys and girls in specialized centres for children with disabilities.²³

5.2 Overview of children and youth with disabilities in Rwanda



It is difficult to determine the precise numbers of persons with disabilities in Rwanda. The National Census (2012) estimates that 446,000 of the total population of 10.5 million people live with cognitive, physical and / or sensory disabilities. Disability prevalence rates for individuals aged 5 and above are estimated to be 5.2 per cent for males and 4.8 per cent for females,²⁴ and those aged 5-18 are said to number 87,900.²⁵ There are no data on prevalence rates for those under the age of 5 nor are data available on the degree of disability. In recent years, the government has been working closely with a number of service providers and advocacy organizations to better estimate the population of adults and children with disabilities and to disaggregate the data in meaningful ways. Such efforts are a necessary step in the development and refinement of services to meet their needs.

Children and youth with disabilities in Rwanda, as elsewhere, share much in common with their non-disabled peers. They require education, healthcare and social services, as well as love, protection, respect and friendship. They and their families need support and assistance so that they can live full, happy lives. Depending on the severity of their impairments, children and young people may need individualized services that promote their growth, development and social integration. These are often difficult to access for financial or social reasons. Rehabilitation services may be costly and located far from home. Many schools are not inclusive and do not admit children with disabilities. Transport costs to health centres can often be prohibitive. Stigma and social pressure may lead some families to keep their children hidden indoors;²⁶ they may feel ashamed to register their child with local authorities and in declining to do so may miss opportunities for support and assistance.

In many parts of the world, children with disabilities are considered to be a burden or a curse on the family and community in which they live.²⁷ Misconstrued assumptions about their intelligence and capacities mean that many of them are socially excluded. Maltreatment and abuse are common, including in Rwanda, where research has shown that children with disabilities are significantly more likely to experience violence than those without disabilities.²⁸ A situation analysis of persons with disabilities conducted in 2017 found that those most likely to experience abuse were girls and children who have hearing / speech or visual impairments.²⁹ In a study conducted by Save the Children in 2010, when asked who were the most vulnerable people in their community, boys and girls without disabilities identified children with disabilities, whom they said were made to work too hard at tasks beyond their capacity and were excluded from playing with other children.³⁰ Moreover, a 2012 study on violence against persons with disabilities conducted in Kigali by Handicap International found that being young and female were two factors that increased an individual's risk of sexual and gender-based violence.³¹ An abundance of evidence demonstrates that having a disability increases and compounds the risks that children and youth face of becoming victims of violence.³²

²³ Primson Management Services. 2018. Summative Evaluation of the Tubarerere Mu Muryango/Let's Raise Children in Families (TMM) Phase I Programme in Rwanda. Kigali: UNICEF and National Commission for Children.

²⁴ <http://statistics.gov.rw/publications/rphc4-thematic-report-socio-economic-characteristics-persons-disabilities>

²⁵ National Institute of Statistics Rwanda 2012.

²⁶ International Centre for Disability and Rehabilitation 2017: 44.

²⁷ See, for example, ACPF 2011; Human Rights Watch 2014; 2015; Njelesan et al. 2018i; Rosenthal 2009; Stopler 2007; Sullivan 2009; UNICEF 2005.

²⁸ International Centre for Disability and Rehabilitation 2017: 41.

²⁹ Ibid.: 41.

³⁰ Save the Children 2010.

³¹ Handicap International 2012.

³² National Council for People with Disabilities & National Commission for Children 2016.

5.3 Service provision



Care and treatment facilities for persons with disabilities in Rwanda have been in place since the late 1950s.³³ The range of services provided has increased dramatically over the years and today centres provide assistance to children and families through a variety of health, education, psychosocial and social protection programmes. While data on the numbers of children reached by these facilities are unreliable, it is clear that the percentage of the population reached by these services remains low; the vast majority of children and young people with disabilities (an estimated 90 per cent at least) live in family and community settings.³⁴

In 2016, the country had 56 institutions providing care for children with disabilities.^{35, 36} The majority of these centres were private institutions established by faith-based, non-governmental, community and parent-based organizations: at that time, it was estimated that more than 80 per cent were receiving at least some funding from national government³⁷ and a similar funding arrangement continues today. Of these institutions, 31 per cent provided residential care only, 29 per cent provided daycare only and 40 per cent provided a mix of residential and daycare facilities.³⁸ Some centres serve the needs of children with particular disabilities, for example, hearing, visual or intellectual impairments.³⁹ Others offer services to mixed groups of children and youth with disabilities. Fifty per cent of all centres offer care to adults as well.⁴⁰ The vast majority of these adults entered the centres as children and have remained, in large part because they have nowhere else to go.⁴¹ The total number of children and young people in March 2016 who were living in or attending 49 of these centres was estimated to be at least 4,300 but almost a third of care facilities did not report figures. Gender and age-disaggregated data are also unavailable,⁴² suggesting that current data is incomplete and unreliable.

In 2016, the National Assessment of Centres Caring for Children with Disabilities in Rwanda found that, of the 49 institutions included in the study, the five most commonly offered services included outreach work in communities, health-related services, physiotherapy, self-care and daily living skills, and support for communication (for example, sign language).⁴³ Most centres also provided educational and vocational services. The quality of these services was variable: a few centres provided quality education by trained teachers or supportive care by trained physiotherapists, and offered decent equipment and facilities; most were ill-equipped, under-staffed and / or employed those without formal training.⁴⁴ Great variation was also evident in the provision of all services and in the quality of care provided to children and youth in these settings.

The Assessment also found that individualized record keeping and care plans, information about entry into care, nature of disability, duration of stay in centres, referral mechanisms, approaches in place to maintain contact with family and to plan for children's exit from care were inconsistently developed and documented.⁴⁵ In many cases, records were found to contain haphazard and incomplete information. The overall findings of the assessment suggest that while a few centres provide highly satisfactory care, treatment and services, many do not meet the basic standards required for the children and youth they serve.⁴⁶ Financial and material support, and training in a range of areas are needed to better meet the needs of children and youth with disabilities living in and attending care centres.

³³ Ibid.: 6.

³⁴ Although prevalence figures are considered to underestimate the true size of the population of children and adults with disabilities in Rwanda, and data from institutions are recognized as incomplete, it is fair to assume that most boys and girls do not reside in care centres.

³⁵ National Council for People with Disabilities & National Commission for Children 2016: 14. While 56 institutions were identified, only 49 met the criteria for inclusion in the assessment.

³⁶ Since TMM was introduced, children with disabilities living in residential centres that provide care to the general population of children have either been reunified with their families, placed in alternative family-based care, or are now living in one of the 56 institutions that specifically serve children and youth with disabilities.

³⁷ National Council for People with Disabilities & National Commission for Children 2016: 23.

³⁸ Ibid 2016: 14.

³⁹ Ibid 2016: 14-15.

⁴⁰ Ibid 2016: 17.

⁴¹ Ibid 2016: 17.

⁴² National Council for People with Disabilities & National Commission for Children 2016: 18.

⁴³ Ibid 2016: 24.

⁴⁴ Ibid 2016: 23.

⁴⁵ National Council for People with Disabilities & National Commission for Children 2016.

⁴⁶ This finding is substantiated in International Centre for Disability and Rehabilitation 2017.

SECTION 6

Findings of the qualitative study

6.1 Context and life in the centres

This study elicited the views and experiences of 39 children and youth ranging in age from 13 to 24 years in 10 different residential and daycare centres. Some of the centres served a broad spectrum of people with disabilities, including those with physical, intellectual and / or sensory impairments. Others catered to the particular needs of those with visual or hearing / speech impairments. This diversity of populations served in the centres visited was reflected in the sample of interviewees, which included 12 males and females who were hearing-impaired, 6 who were blind, 16 who had physical disabilities, 3 with epilepsy and 4 who were described as having intellectual disabilities.⁴⁷ Interview notes referred to this last group as those with ‘mental disabilities’: the conversations transcribed implied that this category included those with cognitive impairments as well as those who had psychiatric and psychological problems. In most cases, it was difficult to follow the thread of these interviews and consequently little of what was said has been included in this report.

The sample of respondents for this study was small and it is not possible to generalize from the reported findings. Nevertheless, in this section, a percentage or numerical breakdown is provided when possible and appropriate so that the breadth and depth of the data can be understood and considered by those interested in programmatic and policy responses to the issues and concerns identified.

The majority of the children and youth interviewed (33 out of 39) stayed at the centres for the bulk of the year, only returning home to their families during holidays and other breaks. The remaining six interviewees lived at home and participated in centre-based activities (such as schooling and physical therapy) on a routine daily basis. A little more than half (22 out of 39) had both parents alive and at home; a further eight stayed with their mother only, one with their father only, and one with their grandmother. The degree of closeness between children and their siblings, parents and other family members was variable; few of those who boarded at the centres reported seeing family during term time. Six children and youth stated that neither parent was alive. Those without parents tended to spend holidays with extended family and family friends.

The vast majority of children and youth interviewed were placed in the centres by their parents or other caregivers after they came to hear about the specialized services on offer. Sometimes parents learned about the centres through word of mouth or through local authorities and service providers, such as physicians or health workers. Occasionally, families were made aware of the possibility of specialized care and education after being approached by ‘white people’ or local and

⁴⁷ The total number of individuals cited according to disability totals 41 rather than 39 because two girls had more than one disability; one was described as having a physical disability and being epileptic, another had both a physical and an intellectual disability.

international organisations who had encouraged them to seek out available services. Media and publicity and awareness campaigns were also said to have motivated families to seek information and assistance. These ways of accessing care and services echo those identified in the 2016 National Assessment of Centres Caring for Children with Disabilities in Rwanda⁴⁸ and the 2012 National Survey of Institutions for Children in Rwanda.⁴⁹

Several different service and programme models were found.⁵⁰ Directors, head teachers and administrators described a mix of day centres, boarding schools / care facilities, and centres that offered the option of both day attendance and residential care. Approximately half of the key informants for this study worked in settings that provide integrated schooling, enabling children with and without disabilities to study and learn together. The other half worked exclusively with children and youth with disabilities.

Education was the primary service offered by the centres where this research took place.⁵¹ Boys and girls with disabilities who were unable follow the national curriculum in its standard form were provided with an adapted programme that enabled them to learn at their own pace. Usually this involved the use of specialized teaching methods, such as braille and sign language. Most of the centres also provided a variety of medical and psychological support services, including fitting prosthetics, physiotherapy, dispensing medication, counselling, and music therapy. Among those with outreach services, emphasis was placed on the engagement of parents, specifically through the provision of support and counselling to enable them to come to terms with the challenges they faced raising a child with a disability.

“We also do counselling for both children and their parents. Sometimes we receive children who have a kind of trauma because they are stigmatized in the Rwandan society and we do counselling for them and for their families because most of the time they don’t know how to handle those children. Therefore, we help them and tell them that those children are humans like any other children, that they are a gift of God, that they have to take that gift and help them within their means. Parents come once a month, we train them, and those who are able, go and teach others.”

-(Key informant)

In addition to education and health services, all of the centres involved in this study offered a variety of leisure activities. These included sports (e.g. swimming, football, basketball and volleyball) and / or music lessons, as well as vocational skills training (e.g. tailoring, sewing, weaving, embroidery, carpentry, masonry, cultivating and animal husbandry). Computing skills also appeared to be increasingly available through the national ‘one computer per child’ programme.

While each individual centre did not necessarily offer all of the services and activities described, all offered both education and leisure activities. Those that did not have specialized medical facilities reportedly ensured that relevant treatment and medical support was made available to the children and youth outside the centres. In such cases, centre staff accompanied the children and young people to hospital and to collect health insurance cards to pay for treatment. Some centres made home visits to support families and children and youth, identify the challenges they faced and link them with relevant support services. Because the sample of institution staff involved in this study was small, it is not possible to know whether this was a common approach across the country.

All of the children and youth interviewed described a highly structured day and each centre appeared to follow a very similar routine. The children’s mornings and afternoons were organized around their school lessons, prayer times and mealtimes. Once classes were finished, typically around 4.30pm, the children were engaged in different activities such as sport and music, cleaning and study time.

“Here we study twice per day ... we study in the morning and in the evening. Since 7.20am up until 4.30pm we are in class and lessons follow each other as the curriculum has been designed.”

– Male aged 19

“At 4.30pm we leave classes for different activities such as sports, others are in different choir rehearsals, and so on. And at six o’clock we go to take dinner, and at 7.10pm we go to have self-studies, at nine o’clock it’s bedtime.”

– Male aged 20

The busy daily schedules described by children, youth and centre staff stand in stark contrast to the often empty, lonely and idle days that boys and girls described at home, where few activities were accessible to them and where communication and mobility challenges made it difficult to venture out.

⁴⁸ National Council for People with Disabilities & National Commission for Children 2016.

⁴⁹ Hope and Homes for Children Rwanda 2012.

⁵⁰ National Council for People with Disabilities & National Commission for Children 2016.

⁵¹ International Centre for Disability and Rehabilitation 2017.

6.2 Perceived benefits of living in residential care



Children and youth were overwhelmingly positive about their lives in the centres. Residing among, or spending time with, others with disabilities was by all accounts considered to be a liberating phenomenon. With no one ignoring them, or staring at them, interviewees reported feeling relaxed and at ease. They emphasized the pleasures they found in social interaction, their ability to make friends easily and the simplicity of living and being with people who do not judge them and who accept them as they are, a sentiment also shared by child respondents in the 2016 National Assessment of Centres Caring for Children with Disabilities in Rwanda.⁵² This recognition of themselves as persons – as girls, boys, young women and young men who not only can engage with the world around them but who have something to offer that world – helped them to open themselves to the learning and opportunities available in the centres. This shared experience of being a child or young person with a disability was understood to be the most significant benefit of spending time in the centres, and children and youth were unanimous in according it tremendous value:

“When I started before coming here, I lived a bad life. I was unable to meet others and talk so that I can expand my knowledge. But here, I am able to talk with my fellows, and know how they are doing.”

– Male aged 20

“Disabled children in the countryside are not treated like other children, so this prevents them from being open to other children and their lives become bad whereas when we are here at school we are treated the same and we feel happy.”

– Female aged 15

Living in or participating in the activities of the centre enabled children to understand that they were not alone, that there were other children who have similar disabilities.

“She enjoys being with others who have the same disability and that she isn't alone.”

– Interviewer describing overall impressions after interview with female aged 13

Being with other disabled children also helped boys and girls to appreciate that there are some people who are worse off than them but who nevertheless are capable of doing things and leading a good life. In fact, in the centres, much emphasis was placed on helping those with disabilities to understand that they are human beings and that they can set and achieve goals and can contribute to society. Several respondents spoke of their experiences in the centres enabling them to be hopeful about the future and to believe that they can participate just as an able-bodied person can.

“Right after losing my leg...I did not accept my situation because before I used to go to school on both feet; this hurt me. At first, I was even ashamed to join other children, but as I told you, when I reached here, due to the situation of other children I met here, I regained hope and felt strong. My mates trust me and school authorities support me. As a result, I'm among student representatives. In short, they consider me as an able person.”

– Female aged 16

“Everything is fine; I realized that not just boys are blind. I learnt to write, and learnt to read scriptures for blind people. I am happy to be in a place where others have the same problem. The children are hopeful and have accepted it [their condition] to the extent that they can do everything a person who is not blind can do.”

– Male aged 20

“I feel proud whatever my condition. I am satisfied and I am not afraid of the future. I feel that from now on I am self-confident and I feel that I can strive for my rights as strongly as possible.”

– Male aged 19

The majority of young respondents reported that they had been able to build good relationships with their peers in the centres; many attributed their happiness in these settings to this closeness. They emphasized how being in the centres enabled them to form trusting friendships in which they exchanged stories, shared secrets and made each other laugh. These pleasures were typically shared with a small group of individuals, usually of the same sex, sometimes with no more than one or two people. Social interactions of this kind were not a regular feature of their lives outside the centres and were thus highly appreciated. Only two of 39 respondents said that they did not have any friends in the centre.

⁵² National Council of People with Disabilities & National Commission for Children 2016: 35.

“I have one friend who is a girl, we understand each other on everything, we help each other, most of the time when you miss me you can ask her and she gets me because we are often together, we advise one another, I cannot do anything without her advice and the other way round.”

– Female aged 15

One element of life in the centres about which children and youth were particularly positive was the fact that friends were there to help if something went wrong or to assist if they were sick or needed assistance because of their disability. This help took place between two children with disabilities but also, in centres where schooling was integrated, it could be offered by a child without a disability, a relationship which was hugely appreciated and normalizing for children and young people in the centres:

“Something that makes me very happy here at the school is to see my colleagues without disabilities helping the one with disability, such as helping them to sit on a wheelchair or to help one another in general. These things make me feel as if we are people without disabilities in society, we share whatever with others and we practice sports together without any problem.”

– Male aged 17

When asked about the people that they trusted within the centres, children and youth overwhelmingly referred to the supportive role played by their peers. Only three out of the 39 respondents mentioned that they trusted and relied upon the staff at the centres. It is not possible to know why relationships with staff were not more widely reported. However, because the structured questionnaire asked respondents specifically if there were friends or ‘anyone else’ whom they trust, it could be that discussions defaulted to being about the named category of ‘friends’. Further probing about other important people in their lives did not take place. The few children and youth who did speak about the supportive role played by staff appeared comfortable to seek assistance when they had a problem, be it medical, academic or with friends, and to receive help as needed to resolve the issue.

“Our leaders take care of us, they want to know on a daily basis the problems of disabled people, they show us love.”

– Female aged 18

“The administrators are friends such as the teacher and the person responsible for the welfare of children, if she raises problems she attends to them immediately.”

– Female aged 19

Much emphasis was placed by child and youth respondents on the learning opportunities provided by the centres. They stressed the value of these programmes for improving their future prospects and appreciated the fact that in some cases schooling was university-preparatory. Having good teachers who understood their disabilities and could communicate with them was greatly valued, particularly by children who used sign language: “Signing and playing with other children is what pleases me most.” (Male aged 14). These efforts to provide accessible education for children and youth with special needs reflects the commitment of many centres to implement the national ‘education for all’ policy and to ensure that children’s basic right to education is upheld.

“When a centre manages to put them together and offers them basic education they manage to contribute to the development of their society and the latter integrates them because of their role; their right to an education and life like others, must be upheld.”

– Centre staff in FGD

Furthermore, administrative and programme staff in centres asserted that providing children with disabilities with the opportunity to learn helped to change people’s attitudes towards them, both within the centres and also at home and in the community. A number of key informants noted that when a parent saw their child’s physical, emotional and academic development, they began to recognize the child’s capabilities in terms of learning and performing tasks independently. This exposure could be transformational in terms of parental attitudes and behaviours: parents were said to begin to recognize their child’s value and worth, and the possibilities that he or she had to live a full life as a contributing member of society. Centre staff who were interviewed and who participated in the focus group discussions strongly asserted that this ability was nascent in nearly all children with disabilities, with the exception of those with severe cognitive impairment.

6.3 Perceived challenges of living in or attending residential care



Respondents shared very few of the challenges that children and young people experienced while living in or attending the care centres where this research took place. Children and youth were tremendously positive about the benefits to them of participating in the educational, leisure and social aspects of institutional life. The most negative thing was a comment made by one of the 39 interviewees that she did not like the food and did not feel comfortable. Likewise, administrators, centre staff and other key informants reported no perceived disadvantages to boys and girls associated with attendance or residence in the centres. The questionnaires that guided the key informant interviews and focus group discussions did not include explicit queries on this topic.

However, lengthy discussions about the sometimes limited involvement of parents in the lives of institutionalized children revealed significant concerns on the part of centre staff about the emotional wellbeing of the boys and girls under their care. Teachers, caregivers and others who participated in the focus group discussions were especially troubled:

“Parents won’t come to discuss the special programme needed to help the child.”

– Centre staff in FGD

“Parents take the child to the centre but you don’t always see them there on closing day.”

– Centre staff in FGD

“There are parents who only come here to have their children registered, and once the child is admitted, they may spend a whole year without coming back to follow up their children’s education.”

– Centre staff in FGD

“A parent leaves the child at the centre and never returns to pick up the child so the centre has to help the child during holiday periods too; parents go to the centre and say that they are ‘your children’ - they have given them to the centre.”

– Centre staff in FGD

Centre staff asserted that, without love and affection from their parents, children and youth often felt lonely, sad and rejected. Travel distances and a lack of money to pay for basic transport were recognized challenges for some families but many argued that some parents were all too happy to leave their children in the centre and to relinquish responsibility for their care. Interestingly, these sentiments were not mentioned by any of the children and youth. In fact, all said that they went home during the holidays, including those without parents or in alternative family-based care arrangements. Some said that their parents did not visit because the costs of transport were too high. The veracity of such statements is impossible to assess.

In general, administrators who were interviewed were less frustrated than teachers and caregivers about the level of parental involvement. Nearly all (10 of 12) emphasized the importance of this engagement, and the majority (8 of 12) were hopeful about the increasing success of their efforts to include, support and collaborate with parents:

“Attitudes have changed – before people would consider it a waste to spend money on a disabled child; now parents understand why you need to take care of a child with a disability and educate them. Parents visit them on visiting day and the children go home during the holidays.”

– Key informant

Successful strategies cited by administrators included establishing parent groups to provide mutual support and share information; making attendance at parent-teacher meetings mandatory; requiring parents to contribute to the purchase of uniforms and school materials; offering awareness-raising and information sessions on children’s rights; and hosting discussions on the capacities and strengths of children and young people with disabilities.

“We teach his/her parent to treat the child like others and when the parent has understood, he/she participates in the education of the child, after convincing the parent that the child is like others...to change his/her mindset... it may help the child to build good relationship with others and to love his/her parents.”

– Key informant

The important role that parents play in the wellbeing and development of children with disabilities – as for all children – was widely acknowledged by all respondents. The extent to which institutional care deprived a child of the experience of family life was not, however, problematized. There appeared to be an unspoken understanding that very often the conditions, facilities and support required to care for boys and girls with disabilities at home and in the community are not sufficient to ensure their safe and healthy growth and development.

While not explicitly linked to the quality of children's experiences in the centres, adult respondents were also vocal about the administrative and financial challenges that centres faced. These typically included a lack of funding for specialized facilities and equipment such as wheelchairs, walkers and accessible furniture. They also lamented the need for improved educational and leisure materials, and a lack of trained staff and teachers. The implication of these assertions is that boys' and girls' lives would be enhanced were the physical settings and material environments within the centres improved.

6.4 Experiences of violence in residential care



This research did not reveal high levels of violence against children and youth with disabilities in the residential care facilities where data were collected. This finding contrasts starkly with the results of many studies with similar populations in other countries.⁵³ However, because the children and young people were not asked explicitly about their experience of physical, sexual and emotional violence in institutional care, any disclosure of abuse in these settings would have to have been revealed through a set of general questions that explored their overall impressions of life in the centres. Moreover, these queries were made at the very outset of the interview, and almost certainly before any rapport could have been developed between interviewer and interviewee. Centre administrators who participated as key informants were also not asked about violence in the centres. Teachers and caregiver staff were asked if they were aware of incidents of physical and sexual violence committed against a child by an adult but not specifically about adults in the centres; this question was asked in only two of the four FGDs. They were also asked about sexual assaults committed by other children and physical disputes between children in the centres but the incidents described were altercations and responses were more about behaviour management and how they support children to improve their communication and conflict resolution skills. These methodological limitations mean that it is impossible to know the extent to which violence affects the children and youth with disabilities who live in and attend care centres.

Although centre staff stated that it was difficult for those who work in the institutions to sexually abuse resident or attending children, one girl (of 20 interviewed) revealed that a security guard had attempted to rape her. Seven others reported having experienced sexual harassment, abuse and assault but none of these instances appeared to have occurred in residential care.⁵⁴ Likewise, a participant in one of the focus group discussions reported that "most of the girls in our centre have given birth and they do not know the men who made them pregnant". The ensuing discussion about the rape of a girl from the centre who was out walking in the community at the time of the attack suggested that these abuses did not take place within the institutions.

It is worth noting that the 2016 National Assessment of Centres Caring for Children with Disabilities found no evidence that sexual abuse occurs when children are in residential care, although pregnancies among resident girls were also observed but not investigated. The authors of the study suggest that these may have occurred because of insufficient overnight supervision of single sex dormitories.⁵⁵ They do not hypothesize whether the pregnancies resulted from consensual unions.

6.5 Experiences of violence in families and communities



A systematic review of the prevalence and risk of violence against children with disabilities around the world found that boys and girls with physical, intellectual and/or sensory impairments were substantially more likely to experience physical, sexual and emotional violence than their peers without disabilities.⁵⁶ The Rwanda National VACYS conducted in 2015 reported that 36 per cent of girls and 48 per cent of boys aged 13-17 years had experienced some form of violence in the twelve months prior to the survey.⁵⁷ This survey did not include data on violence against children and youth with disabilities. The findings of this qualitative study offer some insights into the types and prevalence of violence experienced by this particular group of young people and suggest important areas for service delivery, programme design and further research.

⁵³ See, for example, ACPF 2011; Disability Rights International 2007; 2010; Jones et al. 2012; Njelesani et al. 2018; Rosenthal 2009; Stopler 2007.

⁵⁴ The data for the study reveal only the current age of the respondent but not the age at which violence occurred.

⁵⁵ National Council of People with Disabilities & National Commission for Children 2016: 35.

⁵⁶ Jones et al. 2012.

⁵⁷ Rwanda Ministry of Health (MOH) et al. 2016.

Physical violence

Physical violence was the least common type of violence reported by the children and youth who participated in this research. Of the 39 young respondents, 5 reported having experienced physical violence in their lifetime (2 of 20 girls; 3 of 19 boys).⁵⁸ The small sample size means that these figures cannot be considered representative. However, it is notable that they are significantly lower than the rates revealed in the 2015 VACYS, which found physical violence to be the most common form of violence experienced by children, with approximately 4 out of 10 young women and 6 out of 10 young men (aged 18–24) having been exposed to kicking, punching, beating, whipping or other forms of physical violence before the age of 18. Rates were found to be nearly as high among children aged 13–17, 26 per cent (girls) and 42 per cent (boys) of whom reported having experienced physical violence in the past year.

The physical violence disclosed by children and youth with disabilities was perpetrated by a variety of people, including a peer, a neighbour, a sister, a mother and a father. It is not possible to ascertain from the data if it was the child's disability that provoked their abusers, or if other factors were at play. For example, the young woman who reported abuse at the hands of her mother also stated that her mother was an alcoholic and that as a child she had been removed from maternal care and placed with her grandmother, where she received loving and attentive care. Moreover, it is not known whether other non-disabled children in the household also experienced physical violence and to what degree relative to their sibling with disabilities. In general, reports of physical abuse by children and youth in this study were not subject to probing questions. Physical violence in families and communities was also not raised as a concern by centre staff, administrators and others who were interviewed as key informants or participants in focus groups discussions. It is therefore difficult to unpack the findings on this topic.

This research did investigate the acceptability of physical violence among children and youth and it is worth noting that interviewees were overwhelmingly against the use of physical punishment for children, regardless of whether or not they are disabled. The vast majority asserted that children should be advised and counselled and not beaten for their mistakes:

“Physical punishment is wrong. Children should be told about the wrong they have done and be advised.”

– Female aged 19

“Any type of physical punishment is bad, [it] makes you feel worthless...no distinction between those with disabilities and those without.”

– Female aged 17

“It is not appropriate to give any form of physical punishment to any child.”

– Female aged 21

“It is good to give advice rather than physical punishment; it is better to support such children, help them and explain things to them.”

– Male aged 16

A small number of children (3 of 39) qualified their comments by making a distinction between beating a child as a means of punishment or correction for wrongdoing and going too far by wounding or bleeding. Nevertheless, physical discipline was considered unacceptable by nearly all young respondents in this study. These sentiments were echoed by adult administrators and centre staff.

Sexual violence

This study found that sexual violence was far more prevalent among girls and young women with disabilities than was physical violence. While no incidents were reported by boys and young men, 8 of the 20 girls and young women interviewed for this study revealed that they had experienced unwanted sexual harassment (1), unwanted sexual touching (1), unwanted attempted sex (4), and / or rape (1). In one case, the exact nature of the violence experienced was unclear. Because transcripts reveal the age of the respondent but not the age at which these abuses began or occurred, it is not possible to speculate an age range or type of disability associated with a girl's heightened vulnerability. Details of incidents were vague but perpetrators appeared to have been male members of the extended family, and young or adult men in the community.

These findings concur with those described in the VACYS, which suggested that girls were more likely to experience sexual violence than boys. However, the pervasiveness of sexual violence in the lives of girls and young women with disabilities appears to be much higher than among their female peers in the general population. In the VACY survey, 2 out of every 10 young women aged 18–24 were found to have been exposed to sexual violence before age 18; 12 per cent of girls aged

⁵⁸ Respondents were typically not asked at what age or how often this violence occurred.

13–17 reported exposure in the month prior to being interviewed. These figures are much lower than the 40 per cent rate reported in the sample of girls and young women interviewed for this study.

Sexual violence against girls and young women with disabilities was a significant concern among adults working at the institutions where this research took place. No mention was made of the sexual abuse of boys and young men in the interviews with administrators or in the focus group discussions. But centre staff were clear about the particular risks faced by girls:

“Girls can be raped. One can shield them from such violence as long as they are in the centre but the concern is that when they go outside, this happens to them because they are often subjected to violence based on the fact that they will not be able to [report] it.”

– Centre staff in FGD

“A person who is in a wheelchair is raped or abused easily, this is a sexual abuse and surrounding them is another kind of violence, they can be abused by members of their household, workers, family members and neighbours because they can’t fight or deny... there are many incidents of rape.”

– Centre staff in FGD

“When you send them somewhere, especially girls, they can be raped. We have three typical cases whereby you send them to buy something, yet she has dumbness and deafness disability, or she has physical disability, it can probably happen that she is raped. We have cases of girls who were raped and begot without their consent. Some of them are now HIV positive yet their parents are not.”

– Key informant

Several adults asserted that girls were protected only when in the centres, where they are typically supervised or in surroundings restricted to outsiders. Many lamented that this level of protection was not available to girls when they were outside the institutions or in their home communities, where exposure to sexual violence was understood to be a considerable risk to girls and young women with disabilities.

As part of this study, children and youth were asked whether they had been or were engaged in romantic relationships and if so, if they had ever experienced physical or sexual abuse in this context. Twenty of 39 respondents reported that they currently had or had had boy/girlfriends; among these, six reported having had sex (2 girls, 4 boys). None reported having experienced physical abuse but one girl reported sexual violence (details not provided).⁵⁹ The details provided surrounding questions on this topic are not always clear in the interview transcripts.

Emotional violence

Emotional violence was by far the most common form of violence described by the children and youth participating in this study. This violence appeared to take place within families and households and in the community more generally. It took many forms, including wilfully ignoring or insulting a child, or treating a child unequally compared to other children in the household. Ten (of 20) girls and young women reported having experienced emotional violence at home or in the community, as did 11 of 19 boys and young men. Interview transcripts reveal the different ways that individuals experienced and made sense of how that they were treated by others. For example, some children understood derogatory name-calling to reflect the ignorance of the speaker rather than being a malicious attack on them as a person with disabilities. Others appeared more sensitive to these events and described them as intentional acts of cruelty. For example, one 17-year-old boy commented that he had never experienced violence at home but that sometimes leaders in the community ‘used the wrong words’, whereas a 13-year-old girl described feeling insulted when others referred to her as ‘lame’. Given this variation in outlook, similar events may not be similarly understood. Actual rates of emotional violence may vary depending on the experience and viewpoint of the individual.

Despite these qualifications, the experience of emotional violence appears to be much more common among children with disabilities than among the general population of children in Rwanda. In the VACYS, 12 per cent of women and 17 per cent of young men aged 18–24 reported having suffered emotional violence prior to the age of 18 years.⁶⁰ These figures establish emotional violence to be the second most common form of childhood violence in the country but they are substantially lower than the reported rates (of more than 50 per cent) among the children and youth engaged in this study. When in childhood this violence begins, and how long it goes on for, was not investigated by this research, but it is clear that social exclusion, discrimination, stigmatization and cruel and dehumanizing treatment are a feature of life for many boys and girls and young people with disabilities.

⁵⁹ There is some suggestion in one transcribed interview with a girl that she had non-consensual sex with a boy her age when she was 8 years old but the details are unclear and cannot be effectively analyzed.

⁶⁰ Rwanda Ministry of Health (MOH) et al. 2016.

Emotional violence in the family/household

The majority of the children and youth interviewed did not report emotional violence in their home environments. Instead they described being well treated by family members, whom they said were patient and caring and equal in their treatment of all children in the household. A few boys and girls even said that they were treated more favourably than others.

But a quarter of the children and young people (10 of 39) reported feeling belittled, neglected and not valued by some or all members of their family, often their father. Outright insults and abusive comments by parents, siblings and extended family were rarely reported by children and youth. Instead, it was instances of discrimination and unequal treatment that had occurred on an ongoing or one-off basis that appeared to be most common and were experienced as extremely hurtful.

“An example is that I was not sent to school and stayed home only and used to tell my father: “Could you take me to school?” My father answered: “No you are deaf and mute, go away from me, go to wash the clothes, go to cook and he did this constantly. One day I sat sadly and my father asked me why I am sad and I told him I have a problem. He asked me what problem I have and I answered it’s because you don’t want to take me to school and tell me that I have to stay here and he answered yes you have to stay here, where can you go? I was very shocked and another time my sister used to beat me and when I tell my father, he would chase me away showing that we are not equal.”

– Female aged 16

“Her dad was the one who used to say that she won’t be capable of anything in the future, that she should just be left to die (‘it’s only one child’) and he was discouraging her mum so that she doesn’t get money for her treatment. When her mum wanted to sell her piece of land to get money for her treatment, her dad refused saying that they should leave it because she won’t be capable of anything in the future.”

– Interviewer comments on interview with female aged 19

“Once I asked [father] to buy clothes for me and he answered that even if I needed banana leaves that does not make any difference to him. Moreover, there was a time when people who were making the census of children came at ours and asked [father] the number of children he had and when he told the number of children, I was excluded. I was referred to as someone who is extra, as someone who is abnormal with particularities. He said that he had five children and a small ‘disabled’. I was extremely hurt by that word.”

– Male aged 19 years

These experiences were substantiated by administrators and centre staff who participated in interviews and focus group discussions:

“The child may not be hated but he is not valued the same.”

– Centre staff in FGD

“When a child falls sick the parent doesn’t take the child to hospital, parents do not care about his/her health, they pay their (child with mental disability) community health insurance late.”

– Centre staff in FGD

“Parents don’t care about their education, parents refuse to pay school fees because they won’t learn anything.”

– Centre staff in FGD

“In remote areas...you may find that children with disabilities are still isolated by locking them in rooms, being fed like dogs or sometimes not fed at all”; some parents may say, “I have four children and an idiot one.” This goes without saying, that parent does not treat that child as being worthy; the parent does not consider them to have been born the same way as other ones.”

– Centre staff in FGD

“There are even some parents you talk to and they wish their children would die.”

– Key informant

Although parents of children and youth with disabilities were not interviewed for this study, it is clear that they face enormous emotional and financial challenges. With high levels of stigma and shame, parents – most often, mothers – are frequently completely alone in trying to understand, cope with and respond to a child’s needs. For those who live in poverty or without strong social supports in the community, the strain of managing the care of a child with a disability, alongside looking after and meeting the needs of other family members, can be overwhelming. External support services are often inaccessible and specialized care is unavailable in many communities. These pressures do not justify a parent’s rejection of his child but they do highlight the necessity of supporting parents to care for their children in the best way

possible, a point made by several centre staff in the FGDs:

"Families cannot provide for the children; poverty and mindset are the root causes, if they had financial means things would be different."

– Centre staff in FGD

"Another reason is that services to be provided to children with disability are expensive, and as a result, only a few parents can afford to take good care of their children with disability."

– Centre staff in FGD

"A parent may say: if I take care of this one, how will others be able to live?"

– Centre staff in FGD

"A child with a disability is considered the mother's child and the husband will leave her. The mother is left to beg on the streets with that child; she will [ask] "[I cannot] pay the fees for that dunce instead of paying for the one who will take care of me. Who will know look after me during my seventies, who will help me in hard times?"

– Centre staff in FGD

Families, especially mothers, plainly face significant challenges to providing loving, attentive and unbiased care to their children with disabilities. The statements made by the children and young people interviewed for this study shed light on the personal impact of these difficulties on their relationships and sense of belonging and respect within the household. The diminished expectations of parents and their discriminatory attitudes and behaviours have profound consequences for the mental health and wellbeing of children and youth with disabilities. Some interviewees reflected on feeling unloved:

"In 2007, his big brother died and his grandmother said that a person without disability has died and the deaf and dumb person lives on which was very upsetting, inside he felt he was good for nothing; it happened several times: 'It is one bad word after another, and then you feel deeply sad beyond bearing... this psychological abuse makes you sink in sorrow."

– Interviewer comments on interview with male aged 19

"At home, she is alone and lonely, she feels like she is being harassed; she doesn't feel free; no one comes to talk to her, she is lonely – 'In the morning I wake up and move around, when I am at home no one cares about me. No one can call me for a talk, no one can assign me a job, I live in total loneliness'"

– Interviewer comments on interview with female aged 18

"She feels like her mother has rejected her."

– Interviewer comments on interview with female aged 17

These feelings of loneliness and isolation appear to be particularly acute among children and youth who are deaf and unable to speak. Outside the centres, it was revealed that virtually no one can use sign language, including, often, family members. "No one in my family knows sign language, and no one is willing to interact with me." (Female aged 24). Children and young people reported feeling considerably isolated and saddened by this reality.

Emotional violence in community

This study revealed that verbal abuse, harassment and discrimination against children and youth with disabilities are common in the public sphere. Neighbours and others well-known to children are rarely the perpetrators of this violence. Rather, it appears that those responsible – both children and adults – are strangers. Children and young people are frequently called names, mocked, belittled and ostracized because of their disabilities.

"People often stare and ask questions; some people / children say bad words 'ikimuga' and 'karema', which is hurtful but there is nothing you can do about it. It makes you feel like they don't like you, that they don't value you; they often say: 'That "kimuga" is studying, but what for? How will it help its parents?' I kept that in my mind and it hurt me."

– Female aged 17

"Children and youth with disabilities are victimized, insulted and treated as being worthless, they are harassed a lot; they say that they are disabled and incapable of doing anything."

– Female aged 13

"Many of us are treated that way. You will hear people saying: 'That one is crippled, stupid, dirty, can't take care of themselves', and so on. For people with blindness, people with deafness and dumbness, or any other handicapped person, others say that they are stupid or crazy. I become very sad when I witness that... many people think that people with disabilities are worthless, some won't even talk to them."

– Female aged 19

Adult participants in focus group discussions also reported this insulting and abusive treatment.⁶¹ It is encouraging to note, however, that many respondents in this study, including several children, noted some improvement in recent years in terms of how boys and girls and young people with disabilities are treated, especially in less remote settings. Whether these changes can be attributed to improved access to services, the greater visibility of disabled people in public life, awareness-raising about the equal rights of all children, the implementation of policies such as 'education for all', or other reasons, is not known. It is nevertheless clear that such changes are welcome:

"Today there has been an improvement in the life of children with disabilities. In the past days, such children were stigmatized, but today, though it has not reached 100 per cent because in some communities people have still kept their stereotype and have not yet understood that a person with disability is a human being like others, in general they understand it, though it has not reached a big percentage [yet] so that those children be treated like others and be given their value."

– Centre staff in FGD

"In the past they used to call them names and would dehumanize them but now they give them the dignity they deserve; in general there is no big problem where he lives; neighbours treat him like an intelligent person; 'They see me for instance, explaining lessons to other fellow children who are not blind, they are surprised and say that even a disabled person is able.'"

– Interviewer explaining comments made by male aged 15

In sum, the findings of this study suggest that emotional violence is a common experience for many children and youth with disabilities. Some of this violence takes place in the household and among siblings, perpetrated by parents (usually fathers) and other family members who discriminate against and isolate those with disabilities. Strangers in the community are also responsible for mistreating children and young people with disabilities, and tend to do so in explicit and direct ways, for instance through insults and name-calling. One of the most damaging impacts of these experiences on boys and girls is that they are often surrounded by people who have minimal expectations for what they can contribute and accomplish in their lives.

6.6 Disclosure and reporting of abuse



The most significant finding of this study regarding the disclosure of abuse is that children and youth sometimes inform family members or close friends when they have experienced maltreatment or violence, but they appear rarely to report these experiences to the authorities.

At the family level

As discussed in Section 6.5, only 3 of 39 children and youth interviewed for this study reported having experienced physical violence at home. Ten others described having been insulted by siblings, parents or other household members about their disability, or discriminated against or excluded from participating in family life and/or schooling. The questionnaires that structured the interviews with children and young people asked what actions individuals have taken when they were treated poorly or when they experienced violence in the household. However, these questions were inconsistently asked, and when they were, the common response of 'no one' was typically not probed. Although there are insufficient data to explore if or to whom children and youth disclose or report family violence, it seems it is very rare to do so.

At the community level

The boys, girls and young people interviewed stated that they frequently told their family members when they had been victimized. There appeared to be no hard and fast rule as to when an individual chose to disclose and why she or he decided to do so on certain occasions and not on others. Those with supportive families seemed most likely to approach their mother, although siblings, fathers and grandmothers might also be informed: these were the people outside the centres that children and youth reported to be the most trustworthy and helpful. Some informed friends instead of or as well as family members. Even those who could rely on the care and understanding of others might not share every instance in which they had been treated poorly or cruelly; sometimes boys and girls chose to remain quiet and to live with the situation, particularly when they thought that nothing could be done to change or rectify it.

"She can't tell anyone about her loneliness and harassment...she can't find anyone."

– Interviewer notes explaining comments made by female aged 18

⁶¹ Those interviewed as key informants were not asked about community norms.

“She doesn’t tell anyone when people insult her because she thinks those people can beat her.”

– Interviewer notes explaining comments made by female aged 16

When an individual did disclose abuse, it was common for family to seek out the perpetrator in order to explain the inappropriateness of their behaviour and to make clear the negative impact of such statements or treatment:

“She was insulted once and she told her mum, her mum went to speak to the parents of the children who insulted her and warned them that it’s not good.”

– Interviewer notes explaining comments made by female aged 17

“It is mostly my mum who sympathizes with me and often asks me if I had any problem; and when somebody has disturbed me and I let it be known to her, she quarrels.”

– Female aged 21

Depending on the severity of the abuse, whether verbal or physical, the family member or the child in question might report the incident directly to the local authorities; this practice was described by many children and youth but it is unclear how often it actually happened. When reports were made, it was generally to the village leader or village coordinator. Only in rare instances were the police contacted. It is not clear from the data what, if anything, happened to the perpetrator or what support a child might receive once a case was reported at this level. Studies conducted among children with disabilities in Cameroon, Ethiopia, Kenya, Senegal, Uganda and Zambia⁶² also found a reticence to report abuse to formal justice systems. Neighbourliness and a preference for traditional authorities and local forms of justice that emphasize reconciliation informed family actions in these settings, as it appears to do in Rwanda.

Children and youth also explained that a number of challenges prevented them from seeking help and reporting abuse. In some instances, it was difficult simply because of the distance or access to the local authorities. In other cases, children did not report abuse because they did not know that there was legislation to protect them.

“He didn’t report abusive language because he didn’t know about laws protecting the rights of people with disabilities, he took it as normal behaviour.”

– Interviewer notes based on interview with male aged 20

Children and youth with disabilities also stated that they lack confidence; this was particularly the case among those who are hearing impaired. Because few community members understand sign language, deaf children are often unable to comfortably communicate. They also fear the reactions of people in positions of authority who may laugh at them, intimidate them, call them names or not take them seriously. Experiences such as these have been widely reported by other studies in the region and elsewhere.⁶³

“You can tell authorities but when you use sign language they laugh at you; there is nowhere to report a violent incident. I remember, there was a child with a deaf disability who wanted to go to court, they explained and they didn’t listen and there was no sign language interpreter. Finally, they gave up, and went back home.”

– Male aged 22

“I don’t know what I can do. But it is difficult because I live with deaf disability, they can say lies about me, and I cannot defend myself. It is difficult to talk to people in institutions in charge of protecting people against violence because it is difficult as a deaf and dumb person to talk to them. I can talk to people by typing and they reply.”

– Male aged 18

“People with disabilities may find it hard to find because they don’t know the place or they don’t have any one to show them around or the authorities have a bad understanding, devalue you, accuse you of lying.”

– Male aged 17

These frequently cited challenges suggest that while children and youth knew where they could go to report an incident, they were unlikely to seek support and assistance beyond informing those closest to them. This finding was also established for children and youth more generally in Rwanda by the national VACYS, which identified several barriers to accessing help, such as a belief among boys and girls and youth that they were at fault or that violence was not a problem.

⁶² ACPF 2011; Stopler 2007.

⁶³ ACPF 2011 (Cameroon, Ethiopia, Senegal, Uganda, Zambia); Stopler 2007 (Kenya, Uganda); Njelesani et al. 2018 (Guinea, Niger, Sierra Leone, Togo); BCN & EveryChild 2011 (global).

Within the centres

As discussed in Section 6.2 above, the children and youth were overwhelmingly positive about their lives in the care centres where they live or are enrolled. It is important to note, however, that individual interviewees were asked only about their general impressions of the centres and where, in general, they feel safe and unsafe. No questions were asked about exposure to violence in institutions.

Similarly, administrators and other key informants were not asked about violence in the centres. Centre staff who participated in focus group discussions revealed instances of sexual violence against girls in the institutions where they worked, but these were understood to have occurred in the surrounding communities rather than in the centres. The examples described related to instances where girls became pregnant by men whom they could not or would not identify. Whether such instances were reported and, if so, how they were dealt with by the centres, was not probed.

It is worth noting that in the recently published situation analysis of people with disabilities in Rwanda (2017), interview and focus group participants said boys and girls in institutional care were at greater risk than others of sexual, physical and emotional abuse.⁶⁴ This qualitative study did not investigate this question in sufficient depth to draw any conclusions in this regard but stated that consideration of this issue is an urgent priority.

SECTION 7

Conclusions and recommendations

This study has revealed a number of important findings. The first is that patterns of violence against children and young people with disabilities appear to be different from those experienced by their peers who are not disabled: while physical violence is less pervasive, sexual and emotional violence are more prevalent. Girls and young women are vulnerable to sexual harassment, unwanted sexual touching, assault and rape. Harassment, mockery and verbal abuse are commonly experienced in communities, particularly in more remote areas and in places where individual children and youth are not well known. Unfair treatment and exclusion in the household are a reality for some children; these particularly painful experiences have a negative impact on their mental health and emotional wellbeing. Although there appears to be a growing appreciation of the dignity and rights of people with disabilities among the population at large, discriminatory attitudes and ignorance are a reality with which many boys and girls and young people have to contend. These realities have been widely documented in Rwanda⁶⁵ and elsewhere.⁶⁶

Second, while many children inform family members or friends when they experience violence, very few appear to report these abuses to the authorities, despite knowing that it is theoretically possible to do so. The children and young people who participated in this study described numerous barriers to formal disclosure. Paramount among these are the ignorance of police and local authorities and the practical challenges they face in communicating with them. Perhaps more influential is the view shared by many that there is no point in complaining when they are treated poorly: this, they argue, is the lot in life for a person with a disability. This reality has been commonly reported in other countries in the region, where a dearth of supportive services augments the isolation of those who have experienced violence and increases their risk of continued or escalated exposure.⁶⁷

Third, although parents are often criticized for treating their children unfairly, the challenges that mothers and fathers face in raising a child with disabilities are widely acknowledged and understood by those who provide care and services. There is a recognized need to reach out to parents to build their awareness and understanding and to improve the accessibility of services so that they are able to keep their child at home without compromising the child's development. This point has been made repeatedly in other studies, most recently in the 2016 Report on National Assessment of Centres Caring for Children with Disabilities in Rwanda and the 2017 Rwanda Disability Situation Analysis Report.

Fourth, children and youth living in and attending residential care centres attribute great value to the opportunity to live and study among others who share similar experiences and challenges. They describe life in the centres in very positive terms and say that they feel comfortable, engaged and hopeful because of the time they have spent in what they deem to be nurturing social and educational environments. They cherish their friendships and many enjoy romantic relationships

⁶⁵ See, for example: International Centre for Disability and Rehabilitation 2017; National Council for People with Disabilities & National Commission for Children 2016. African Child Policy Forum 2011; Better Care Network and EveryChild 2012; Handicap International 2012.

⁶⁶ See, for example: African Child Policy Forum 2011; Better Care Network and EveryChild 2012; Handicap International 2012.

⁶⁷ African Child Policy Forum 2011; Meinck et al. 2015; Njelesani et al. 2018.

with peers. Some are sexually active. This finding is not surprising, given the significant challenges many boys and girls and young people face in their home communities. Nevertheless, it rests uneasily alongside widespread efforts to close down institutional care facilities and suggests that children and youth need to be actively involved in the conceptualization and articulation of the supports and services that they feel are important to their personal wellbeing and development.

Fifth, despite the significant challenges that many face, the majority of children and youth describe feeling loved and well cared for within their families. They appreciate the support their parents, siblings and others give them. More than anything, they want to feel a sense of belonging and to be treated as equal to their siblings and to other children in the household. These priorities are not unique to boys and girls with disabilities, or to Rwandan children more generally. They are the concerns of children and young people the world over, and should be the impetus behind efforts to improve their care, protection and wellbeing.

Recommendations

Recommendations for how to reduce the exposure to violence among children and youth with disabilities are outlined below.

Accessibility and inclusivity of services

- Policy makers, local authorities and service providers should work with families to improve the accessibility and inclusivity of existing programmes and to develop new, wide-ranging support at community level. The aim, as far as possible, should be for children and youth to access services while remaining in their families. Daycare services should therefore be emphasized.
- Children and youth with disabilities should be provided with practical, accessible information on sexual health. They need to have healthy sexual relationships and to be able to protect themselves from sexually transmitted infections, pregnancies, abuse and exploitative relationships.

Reintegration and family-based care

- Children and youth living in residential care who could be safely and appropriately cared for in their families should be reintegrated and enabled to access education, medical, psychological and rehabilitation services from these settings. For those who cannot be returned to their families, community and family-based alternatives to residential care and services should be explored.

Community-based support for families

- More opportunities should be created for families caring for children with disabilities to come together to share experiences, support one another and derive strength from the recognition they are not alone in the challenges that they face.
- Safeguarding measures should be put in place to protect children and youth with disabilities from exploitation and abuse.
- Focused efforts should be made to work with fathers (who appear more likely than mothers to ostracize or reject a disabled child) so that they are better able to appreciate the unique strengths, worth and dignity of all children, including their own. Doing so could involve engaging parents and/or people with disabilities to share positive examples of what they have achieved and the types of support they have needed along the way. More opportunities should be created at the community level for families with children who are deaf to learn sign language. Health workers, police, teachers and others should be encouraged to take part in these learning sessions.
- Sensitization efforts that help community members to understand the needs and capacities of children and young people with disabilities should be introduced in order to dispel the ignorance and fear that informs much of the cruel and discriminatory behaviour that persists in the public sphere. Practical, creative activities that include all children could go a long way towards demonstrating that children with disabilities can get involved and contribute to society.
- Social protection initiatives should target families living in poverty who have children with disabilities.
- Further research should be carried out on parents'/caregivers' experiences of caring for youth and children with disabilities in families and communities.

References

- African Child Policy Forum (2011).** Violence against Children with Disabilities in Africa: Field studies from Cameroon, Ethiopia, Senegal, Uganda and Zambia. Addis Ababa: The African Child Policy Forum.
- Better Care Network & EveryChild (2011).** Scaling down. Reducing, reshaping and improving residential care around the world. London: EveryChild.
- Better Care Network and EveryChild (2012).** Enabling reform: Why supporting children with disabilities must be at the heart of successful child care reform. Better Care Network: New York.
- Black, M. C. et al. (2006).** 'Telephone survey respondents' reactions to questions regarding interpersonal violence'. *Violence Vict.* 21(4): 445-59.
- Browne, K. D. (2009)** *The Risk of Harm to Young Children in Institutional Care*, London: Better Care Network and Save the Children.
- Disability Rights International (2007).** Torment not Treatment: Serbia's segregation and abuse of children and adults with disabilities. <https://www.driadvocacy.org/wp-content/uploads/Serbia-rep-english.pdf>
- Disability Rights International (2011).** Abandoned and Disappeared: Mexico's Segregation and Abuse of Children and Adults with Disabilities. <https://www.driadvocacy.org/wp-content/uploads/Abandoned-Disappeared-web.pdf>
- Draucker, C. (1999).** 'The emotional impact of sexual violence research on participants'. *Arch Psychiatr Nurs.* 13(4): 161-169.
- Du Mont, J. & L. Stermac (1996).** 'Research with women who have been sexually assaulted: Examining informed consent'. *Canadian Journal of Human Sexuality.* 5(3): 185-191.
- Ellery, F., G. Landsdowne & C. Csaky. (2011).** *Out from the Shadows. Sexual Violence Against Children with Disabilities.* London: Save the Children and Handicap International.
- Handicap International (2012).** An assessment of the factors of risk and vulnerability of women and men with disabilities to sexual and gender-based violence. http://www.hiproweb.org/uploads/tx_hidrtdocs/RwandaSDRS05.pdf
- Hein, I. M. et al. (2014).** 'Accuracy of the MacArthur competence assessment tool for clinical research (MacCAT-CR) for measuring children's competence to consent to clinical research'. *JAMA Pediatr.* 168(12): 1147-53.
- Hope and Homes for Children Rwanda (2012).** *National Survey of Institutions for Children in Rwanda.* Kigali: Hope and Homes.
- Human Rights Watch (2014).** *Abandoned by the state: Violence, neglect and isolation for children with disabilities in Russian orphanages.* New York: Human Rights Watch.
- Human Rights Watch (2015).** "Treated Worse Than Animals" Abuses against women and girls with psychosocial or intellectual disabilities in institutions in India. New York: Human Rights Watch.
- International Centre for Disability and Rehabilitation (2017).** *Rwanda Disability Situation Analysis Report.* Kigali: UNICEF Rwanda.
- Jensen, T. K. et al. (2005).** 'Reporting possible sexual abuse: a qualitative study on children's perspectives and the context for disclosure'. *Child Abuse Negl.* 29(12): 1395-413.
- Jeste, D. V. et al. (2007).** 'A new brief instrument for assessing decisional capacity for clinical research'. *Arch Gen Psychiatry.* (8): 966-74.
- Jones, L. et al. (2012)** 'Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies'. *Lancet.* 380 (9845): 899-907.
- MacQueen, K. M. et al. (2014).** 'Comparison of closed-ended, open-ended, and perceived informed consent comprehension measures for a mock HIV prevention trial among women in Tanzania'. *PLoS One.* 9(8):e105720. doi: 10.1371/journal.pone.0105720.
- Meinck, F. et al. (2015).** 'Risk and Protective Factors for Physical and Sexual Abuse of Children and Adolescents in Africa: A Review and Implications for Practice'. *TraumaViol Abuse.* 16: 81-107.
- Miller, C. K. et al. (1996).** 'The Deaconess Informed Consent Comprehension Test: an assessment tool for clinical research subjects'. *Pharmacotherapy.* 16(5): 872-8.
- National Council for People with Disabilities & National Commission for Children (2016).** *Report on the National Assessment of Centres Caring for Children with Disabilities in Rwanda.* UNICEF: Kigali.
- National Institute of Statistics of Rwanda (2012).** *Fourth Population and Housing Census.*
- National Institute of Statistics of Rwanda (NISR), Ministry of Health of Rwanda (MOH) & ICF International (2012).** *Rwanda Demographic and Health Survey 2010.* Calverton, Maryland, USA: NISR, MOH, and ICF International.

Njelesani, J. et al. (2018). 'From the Day They are Born: A Qualitative Study Exploring Violence Against Children with Disabilities in West Africa'. BMC Public Health. 18:153.

Plan International (2016). Tackling Exclusion Framework. London: Plan International.

Priebe, G., M. Backstrom & M. Ainsaar (2010). 'Vulnerable adolescent participants' experience in surveys on sexuality and sexual abuse: ethical aspects'. Child Abuse Negl. 34(6): 438-447.

Primson Management Services (2018). Summative Evaluation of the Tubarerere Mu Muryango/Let's Raise Children in Families (TMM) Phase I Programme in Rwanda. Kigali: UNICEF and National Commission for Children.

Rosenthal, E. (2009). The Rights of Children with Disabilities in Viet Nam. New York: UNICEF and Disability Rights International.

Rwanda Ministry of Health (MOH), Ministry of Gender and Family Promotion (MIGEPROF), Ministry of Education (MINEDUC), National Commission for Children, National Institute of Statistics of Rwanda (NISR), UNICEF Rwanda, & the US Centers for Disease Control and Prevention (CDC) (2016). Violence Against Children and Youth in Rwanda: National Survey Results (2015). Kigali, Rwanda.

Save the Children 2010

Stopler, L. (2007). Hidden Shame: Violence against children with disabilities in east Africa. Amsterdam: TDH Netherlands. <http://www.firah.org/centre-ressources/upload/notices3/2007/hiddensham.pdf>

Sullivan, P.M. (2009). 'Violence exposure among children with disabilities'. Clin Child Fam Psychol Rev. 12(2):196-216.

United Nations (1989). Convention on the Rights of the Child. New York: United Nations.

United Nations (2006). Convention on the Rights of Persons with Disabilities. New York: United Nations.

United Nations (2010). Guidelines for the Alternative Care of Children. http://ap.ohchr.org/documents/dpage_e.aspx?si=A/HRC/11/L.13

United Nations (2011). Disability and the Millennium Development Goals. A Review of the MDG Process and Strategies for Inclusion of Disability Issues in Millennium Development Goal Efforts. New York: United Nations.

UNICEF (2005). Secretary General's report on violence against children thematic group on violence against disabled children: Findings and recommendations. New York: UNICEF.

UNICEF (2010). At home or in a home? Formal care and adoption of children in Eastern Europe and Central Asia. Geneva, Switzerland: UNICEF.

UNICEF (2014). Hidden In Plain Sight. New York: UNICEF.

Walker, E. A. et al. (1997) 'Does the study of victimization revictimize the victims?' Gen Hosp Psychiatry. 19(6): p. 403-10.

Williamson, J. & A. Greenberg (2010). Families Not Orphanages. Better Care Network Working Paper. <http://www.crin.org/docs/Families%20Not%20Orphanages.pdf>

Winters, N., L. Langer & A. Geniets (2017). 'Physical, psychological, sexual, and systemic abuse of children with disabilities in East Africa: Mapping the evidence'

WHO (2001). Putting Women First: Ethical and Safety Recommendations for Research on Domestic Violence Against Women. Department of Gender and Women's Health, World Health Organization: Geneva, Switzerland.

WHO & World Bank (2011). World Report on Disability. Geneva: WHO. http://www.who.int/disabilities/world_report/2011/en/index.html

Annex A

Snapshot of research sites

PROVINCE	DISTRICT	INSTITUTION NAME	SERVICE PROVIDED	BENEFICIARIES		
				M	F	TOT
KIGALI CITY	NYARUGENGE	Institut Filipo Smaldone	Special education	75	100	175
	GASABO	Jyamubandi Mwana	Special education	34	31	65
	KICUKIRO	Izere Mubyeyi	Special education			117
NORTHERN	RULINDO	Maison d'Accueil d'Esperance Pain	Inclusive education	43	31	76
SOUTHERN	NYANZA	Hvp Gataraga	Special education and rehabilitation			655
	Nyaruguru	Educational Institute of Blind of Franciscan Sisters Servants of The Cross	Special education	40	56	96
	HUYE	Centre des Sourds Muets Eds Freres de Saint Gabriel	Special education	78	81	159
EASTERN	Nyagatare	Ecole des Sours Muets de Nyagatare	Special education	46	40	86
	Rwamagana	Hvp Gataraga	Special education	94	104	198
WESTERN	RUSIZI	Centre des Handicapes de Nkanka	Rehabilitation centre	80	82	162
	RUTSIRO	Centre Komera	Education and rehabilitation for life	63	48	111
	NGORORERO	Ineza Kabaya	Special education	38	47	85
	NGORORERO	Apax Muramba	Basic education and vocational training	24	21	45
	RUBAVU	Ubumwe Community Centre	Special education	98	108	214

Annex B

Lead institutions and key partners in the study

Study Sponsors: Ministry of Health – Rwanda Biomedical Centre (RBC)

United Nations Children’s Fund (UNICEF) Rwanda
National Council of People with Disabilities (NCPD)
National Commission for Children (NCC)
Ministry of Gender and Family Promotion (MIGEPROF)

Investigators: Rwanda Ministry of Health / Rwanda Biomedical Centre

Yvonne Kayiteshonga, Principal Investigator
Mechilde Kamukunzi, Co-Principal Investigator
Alypio Nyandwi, Co-Investigator
Jean Damescene Iyamuremye, Co-Investigator
Jeane D’Arc Dusabeyezu, Co-Investigator
Nancy Misago, Co-Investigator

UNICEF Rwanda

Genevieve Uwamariya, Co-Investigator

National Council of Persons with Disabilities

Marcel Nkurayija, Co-Investigator

Ministry of Gender and Family Promotion / National Commission for Children

Germaine Mukabalisa, Co-Investigator
James Wayo, Co-Investigator
Josianne Mukamana, Co-Investigator
Anastasie Nyirabahinde, Co-Investigator

University Teaching Hospital of Kigali

Emmanuel Hakomeza, Co-Investigator

United States Centers for Disease Control and Prevention

Ansley Lemons, Co-Investigator
Laura Chiang, Co-investigator

Annex C

Risk assessment

This study employed the following risk assessment guidelines and processes.

Description of risks

There is evidence suggesting that many people find it beneficial to talk about their experiences of violence and they appreciate the opportunity to be asked questions about it.⁶⁸ There is also evidence that adolescents and young adults are willing to talk about their experiences of abuse within a supportive structure.⁶⁹ Nevertheless, there is still the potential for minimal risk due to the content of some of the questions and the possibility that someone may learn of the nature of the study. In regards to the content of the questions, risk was minimized through sensitivity training for the interviewers. The participants were also informed before the interview that if they were uncomfortable answering any question they could skip it, and they could stop the interview at any time.

Regarding the possibility that someone might learn about the interview, this risk was minimized by conducting the interview in a safe, private place and by using the carefully constructed consent process, detailed in Annex D, to further ensure that other members of families or institutional staff were not aware the interview focused on violence. Therefore, this research study involved only minimal risk of harm to subjects.

Anticipated benefits

There were no direct benefits to the participants. However, a list of local and national services and sources of support, including services with a disability focus, were offered to all CYWD and caregiver staff participants, which could be beneficial to participants by increasing their awareness of existing community and national resources. For participants who became upset or felt unsafe, the study team offered to directly refer and link them to support services. This might benefit the participant by providing help and support they might not have otherwise accessed. In addition, there is evidence that some people find that talking about their experience of violence, even in the context of a study, may actually help them heal; this might have been an added, unintended benefit for participants in this study.

⁶⁸ Draucker 1999; Du Mont & Stermac 1996; Walker et al. 2006; Black et al. 2006; Priebe, Backstrom & Ainsaar 2010.

⁶⁹ Jensen et al. 2005.

Annex D

Informed consent procedures

It was determined that the study involved no more than minimal risk of harm to subjects and did not involve any procedures for which written consent is normally required outside the research context. In cases in which the documentation requirement was waived, the Institutional Review Board (IRB) required the investigators to provide participants with a written statement regarding the study. Available data indicate that 32 per cent of people in Rwanda are illiterate and that 27 per cent of children with disabilities have never attended school.⁷⁰ As such, CYWD and parents/primary givers undertook an informed verbal consent process, as it was inappropriate to expect those who are illiterate to read and sign a consent form. In addition, a signed informed consent form was the only document linking a participant to the study, as a unique identifier number was used to protect the privacy and safety of participants. This is an added protection for participants to ensure there is no way to link the data to any individuals. By obtaining a written signature from child and youth participants, a risk is introduced that a participant's identity could be obtained from the informed consent form. Consequently, the study investigators obtained a waiver of documentation of written informed consent from children and youth aged 13-17 and adult parents/primary caregivers.

Institution administrators and staff caregivers were expected to have attained an education at a level that enabled them to read and understand the contents of the consent form. Institution administrators and staff caregivers therefore undertook a written informed consent process.

Specifically, CYWD respondents were read the consent form that addresses their rights and welfare as a participant in the study and given time to ask questions. They then provided verbal consent that they agreed to participate. This process was documented by a tick-box and signature of the interviewer on the consent form. In consideration of the sensitive nature of the research, the request for the waiver of signed informed consent by the participant aligns with the investigators' efforts to assure child and youth protections of confidentiality and privacy as well as adherence to WHO guidelines on the subject. The waiver of signed informed consent does this by precluding any potential link between consent forms and participant data.

Age at which participants were considered a minor or adult

According to the United Nations Convention on the Rights of the Child, a child is any person younger than 18 years old, unless the laws of a particular country set the legal age of adulthood younger. This study adhered to this definition, noting that in Rwanda, males or females who have ever been married are considered to be adults. However, the minimum age of marriage in Rwanda is 21. Thus, for this study, any respondent under the age of 18 was considered to be a child requiring parent/caregiver consent for their participation. Any respondent aged 18–24 years old was considered an adult not requiring parent/caregiver consent for their participation.

⁷⁰ National Institute of Statistics of Rwanda (NISR), Ministry of Health of Rwanda (MOH) & ICF International (2012).

Informed consent for CYWD aged 13–17

For eligible CYWD participants in this age group, the institution administrator provided the interviewer with a list of eligible male or female respondents whose parents lived close to the institution. This was to increase the likelihood that parents would be able to come to the institution in person to provide informed consent for their child to participate.

A study interviewer called the potential respondents' parents to tell them about the study's aim to learn about the life experiences of children and youth with disabilities, including perceptions of differential treatment due to having a disability. The interviewer then asked to meet the parent/primary caregiver at the institution to discuss the study further. If they were unable or unwilling to come to the institution, the potential respondent was excluded from the study. The interviewer could also provide information to parents in person during parent visiting days, and could undertake informed consent at the same time if the parent agreed.

Once the interviewer had explained the study further, they sought informed verbal consent from the parent/primary caregiver. The interviewer read the consent form to the parent/caregiver and recorded that the consent procedure has been administered and whether permission to conduct the interview with their child had been granted. This information was recorded via a tick-box and the administrator's signature. Parents were not told that participants would be asked about any physical, sexual, or emotional/ psychological violence they might have experienced. This was to ensure the safety of the participant in the instance that a parent or guardian was perpetrating the violence. The administrator informed the parent/primary caregiver that the interview would be both voluntary and confidential. The above information was given using the Parent/Caregiver Information and Consent Form.

Once consent had been obtained for an eligible CYWD respondent from a parent/guardian, a trained interviewer read the contents of the information and verbal assent form to the child or youth in a private setting. Female interviewers interviewed female respondents; male interviewers interviewed male respondents. The information and consent form introduced the study as an opportunity to learn more about young people with disabilities' health, educational and life experiences in Rwanda. It indicated that participation was completely voluntary and that the interview would take between one and two hours. This form let respondents know that any information they provided would be confidential and would not be shared with anyone; that their decision to take part in the study was completely voluntary; and that they could stop the interview at any time. Respondents were also told that if they chose to participate, they would be asked questions about their sexual activity and their experiences with physical, emotional and sexual violence. Respondents were then asked if they had any questions. Informed verbal assent was obtained from each respondent and recorded via a tick-box and the signature of the interviewer on the consent form. Respondents willing to participate were then interviewed.

Informed consent for CYWD aged 18–24

For eligible CYWD respondents in this age group, the same informed consent process was used as described above, with the exception that the parental/primary caregiver's consent was not necessary. These respondents were administered the initial information form described above. Once the initial information form had been read, the interviewer read the contents of the same verbal consent form. The respondent's verbal consent to participate in the study was recorded via a tick-box and the signature of the interviewer.

Informed consent for CYWD wards of the state

For potential respondents who did not have a parent or primary caregiver, the study interviewer identified the legal guardian and sought their informed consent for the respondent to participate. If the interviewer was unable to identify a legal guardian, the child was excluded from the study.

Additional consent procedures for respondents with intellectual or hearing and speech disabilities

For children and youth respondents with an intellectual disability, comprehension of informed consent and study procedures was an ethical priority. Children assessed as having a higher than mild intellectual impairment were excluded from the study due to ethical issues with ensuring informed consent. A two-stage process was used to assess the respondent's cognitive level and ensure their ability to undertake informed consent. First, institution caregiver staff were asked to select potential child or youth respondents that they either perceived or had assessed as having a low to mild intellectual disability. Before conducting informed consent with any of this group of respondents, the interviewer first administered a comprehension assessment, such as that described and used in other research studies^{71, 72, 73, 74} to ensure the respondent fully understood the study and their rights. Respondents who did not pass the assessment were thanked

⁷¹ Hein et al. (2014).

⁷² MacQueen et al. (2014).

⁷³ Miller et al. (1996).

⁷⁴ Jeste (2007).

for their interest but not enrolled in the study.

For children and youth with hearing or speech disabilities who required sign language interpreters, their informed consent form explained that two interviewers would be used to facilitate the conversation and simultaneously record the interview. One interpreter/interviewer would speak directly with the participant, while the other narrated the conversation aloud for the audio recorder and took notes. The privacy and confidentiality of the interview was stressed, and the interviewers explained the need for two interviewers (i.e. to facilitate the conversation while also recording it aloud without missing vital information). As there is no fully standardized sign language in Rwanda, a sign language interpreter from the Rwanda Deaf Association assisted in those cases where the respondent did not know standard Rwandan sign language. Information about which variant of sign language the respondent used was obtained from institution staff through the screening process.

Institution administrators

A study interviewer approached institution administrators and explained the study's aim to learn about the life experiences of children and youth with disabilities, including perceptions of differential treatment due to having a disability, and asked if they were interested in participating in a key informant interview. The interviewer gave the administrator an information and consent form, which further explained that the study was voluntary, that there were no benefits for them or their institution if they participated, and that all their answers would remain confidential. Written informed consent was obtained from institution administrators and recorded via the name and signature of the respondent and interviewer. Institution administrators were not told that participants would be asked about any physical, sexual, or emotional/psychological violence they might have experienced. This was to ensure the safety of the participant in the instance that an institution administrator was perpetrating the violence. Institution administrators were not interviewed from the same sites as any child or youth respondents.

Caregiver staff

Institution administrators provided information verbally about the study to potential caregiver staff respondents using the Institution Caregiver Information and Consent Form. Study interviewers contacted interested caregiver staff to let them know the date and time of FGDs. On the day of the focus group, the facilitator gave respondents the consent form to read and allowed them to ask questions. If a respondent decided that they were no longer interested in participating, they were thanked for their time and allowed to leave. The caregiver staff's informed consent to take part in the FGD was recorded via their signature on the Institution Caregiver Consent Form. Before beginning the discussion, the facilitator reminded the group of the study's aim to learn about the health, educational and life experiences of young people with disabilities in institutions, and that all information recorded during the discussion would be completely confidential and no identifying information would be included in the study report. The interviewer also reminded participants that their participation was voluntary and the discussion would be recorded so as not to miss any vital information.

Justification for information provided to parents/primary caregivers and institution administrators

According to World Health Organization (WHO) guidelines on gender-based violence research, "It is important that the survey is not introduced to the household and wider community as a survey on violence. Instead, at this level the study should be framed in a different manner – such as a study on women's health and life experiences. However, the woman herself has to be fully informed about the nature of the questions".⁷⁵ For this study, since both males and females can be at risk of victimization of sexual, physical and emotional/psychological violence, these WHO guidelines were applicable to both male and female respondents. However, since the WHO ethical and safety guidelines referred to violence research involving adults, this guideline had to be modified for research involving children and youth in order to take into consideration not only the risk of retaliation against children and youth, but also the rights of parents or primary caregivers to know what their children were being exposed to in the survey.

The consent forms for parental/primary caregivers, institution administrators and caregiver staff therefore stated that the aim of the study was to learn more about the health, educational and life experiences of children and youth with disabilities. The consent form for parents/primary caregivers also mentioned that the interview would include topics such as experiences in school, access to food and goods, health, experiences accessing professional medical and social services, and their relationships with friends, family and community members. This wording was chosen in order to obtain permission to recruit participants from the site and to speak with the study respondent, and as a way to inform the parent/primary caregiver about sensitive topics included in the survey. At the same time, it did not make any reference to violence that might be occurring in the institution or home, and/or being perpetrated by the parent/primary caregiver or other household members or institution staff.

⁷⁵ WHO (2001).

Annex E

Reporting and referral protocol

Reporting of acute cases

If a participant indicated to the interviewer that she or he was in immediate danger, the interviewer activated the response plan for acute cases. The interviewer would immediately alert her or his team leader to the situation and the team leader would immediately call the pre-identified contact at NCC and report this to the relevant officials (including the disability mainstreaming officer at district level) for follow up. The respondent's transcripts and data would not be shared in the referral process.

Appropriate child protection response plans for acute cases were conducted on a case-by-case basis in order to best respond to the individual situation and ensure that the participant was not placed in any additional danger. However, as a basis of action, the team lead and NCC focal point would make every effort to ensure the child was offered immediate help in responding appropriately to a dangerous situation, either in the form of removal from the place of harm, or referral to appropriate medical, psychosocial and legal services, in coordination with responsible agencies and line with national procedures. For cases where the participant was in immediate danger, NCC would make every effort to reach the participant requiring referral within 12 hours. The study investigators anticipated that the number of acute cases would be very few.

In Rwanda, there are mandatory reporting laws for violence against children. It would be very difficult to expect accurate data if there were the obligation to report instances of violence during the study, especially if the reporting is against the participant's will. The Rwanda National Ethics Committee approved the steps outlined in the protocol to ensure the safety and care of any children or youth in present danger of abuse while guaranteeing confidentiality of the respondent and immediate referral to the One Stop Centre and the nearest Police Station.

NCC staff, mental health staff and disability mainstreaming officers from district hospitals who would be handling referrals cases received training on the study and its ethics and confidentiality procedures prior to data collection.

Duty of care to study participants

In Rwanda, community-based health insurance (CBHI) covers the non-public sector population and aims at providing equitable access to quality health services. CBHI are coordinated at the district level, where each of the 30 districts of Rwanda hosts a "Funds de Mutuelle de Santé". Presently, the national health insurance coverage in Rwanda (according to the CBHI database) is 77 per cent. Households are divided into socio-economic levels for payment of CBHI where a pool paid for by contributions from the government and development partners covers the extremely poor.

In most institutions in Rwanda, enrolment in Mutuelle de Santé is mandatory. Where an individual child or youth study participant was not enrolled in Mutuelle de Santé and required support services as a result of their participation, the study would cover the costs of up to five medical, five psychosocial and five legal consultations, for a period of up to one year following their date of study enrolment. However, most services for violence are offered free of charge in Rwanda.

Psychosocial support for study interviewers

The nature of the study topic can be distressing for those conducting the research. For study interviewers that either self-reported or were recognized to suffer from psychosocial distress during or after data collection due to vicarious trauma, team leaders were available to debrief with interviewers at the end of each day and could refer them to the Mental Health Department of RBC, if requested. If they preferred not to be referred, the team leader supported the interviewer internally. Team leaders were trained on this aspect of the study.

Annex F

Global conventions and regional charters related disability and children's care in Rwanda

(Much of this information was derived from Annex 2 in BCN & EveryChild 2011.)

Convention on the Rights of the Child (1989)

Preamble: all children should grow up in a family environment in an atmosphere of happiness, love and understanding, the family should receive necessary assistance to fulfil its responsibilities;

Article 2: the right to protection against all forms of discrimination;

Article 3 & 9: children should not be separated from their parents unless it is in their best interest;

Article 18: parents have the prime responsibility to care for children and states should offer support in helping parents fulfill child-rearing responsibilities;

Article 20: the right of any child deprived of a family environment is entitled to special protection;

Article 23: specifically relates to children with disabilities and recognizes their right to "...enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community"; and "...the right of the disabled child to special care...subject to available resources."

See also relevant rights in relation to freedom from exploitation and abuse, education and development, and health and survival.

The African Charter on the Rights and Welfare of the Child (OAU 1999)

Article 13: outlines the responsibility of the state towards children with disabilities. It requires that all parties to the Charter will use available resources to progressively achieve full access to movement and to public places (and services) for all boys and girls with mental or physical disabilities and the right of such children to special protection measures in keeping with their physical and moral needs and in conditions which ensure their dignity, promote self-reliance and active participation in the community. It further commits every state to "ensure that the child has effective access to training, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration, individual development and his cultural and moral development".

The Standard Rules on the Equalization of Opportunities for People with Disabilities (adopted by the United Nations General Assembly 1993)

Rule 9: Persons with disabilities should be enabled to live with their families. States should encourage the inclusion in family counseling of appropriate modules regarding disability and its effects on family life. Respite-care and attendant-

care services should be made available to families which include a person with disabilities. States should remove all unnecessary obstacles to persons who want to foster or adopt a child or adult with disabilities.

Convention on the Rights of Persons with Disabilities (2006)

This convention emphasizes the need to focus on the child's abilities not disabilities, and on the right to social inclusion, and in particular recognizes the obligations of the state to:

Article 19: "States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right."

Article 23: make provision of support to families in order to ensure against the abandonment or concealment of child with disabilities; "... where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting."

See also relevant articles on non-discrimination, social protection, education, health and the importance of disaggregated data collection.

Guidelines for the Alternative Care of Children (UN 2010)

The Guidelines recognize the family as the 'natural environment' for children and call for a range of high quality, protective care environments for all children who cannot live with their parents. Repeated references are made to children with disabilities, including:

Article 9: "As part of efforts to prevent the separation of children from their parents, States should seek to ensure appropriate and culturally sensitive measures... [t]o support family caregiving environments whose capacities are limited by factors such as disability..."

Article 13: "children must be treated with dignity and respect at all times, and must benefit from effective protection from abuse, neglect, and all forms of exploitation, whether on the part of care providers, peers or third parties."

Article 10: "Special efforts should be made to tackle discrimination on the basis of any status of the child or parents, including ... mental and physical disability."

Article 34 (b): "Supportive social services ... and services for parents and children with disabilities. Such services, preferably of an integrated and non-intrusive nature, should be directly accessible at the community level and should actively involve the participation of families as partners, combining their resources with those of the community and the carer."

Article 38: "States should ensure opportunities for day care, including all-day schooling, and respite care which would enable parents better to cope with their overall responsibilities towards the family, including additional responsibilities inherent in caring for children with special needs."

Article 58: "Assessment should be carried out expeditiously, thoroughly and carefully. It should take into account the child's immediate safety and well-being, as well as his/her longer term care and development, and should cover the child's personal and developmental characteristics, ethnic, cultural, linguistic and religious background, family and social environment, medical history and any special need."

Article 86: "Carers should ensure that the right of every child, including children with disabilities, living with or affected by HIV/AIDS or having any other special needs, to develop through play and leisure activities is respected and that opportunities for such activities are created within and outside the care setting. Contact with the children and others in the local community should be encouraged and facilitated."

Article 87: "The specific safety, health, nutritional, developmental and other needs of babies and young children, including those with special needs, should be catered for in all care settings, including ensuring their ongoing attachment to a specific carer."

Article 117: "Agencies and facilities [responsible for formal care] should ensure that, wherever appropriate, carers are prepared to respond to children with special needs, notably those living with HIV/AIDS or other chronic physical or mental illnesses, and children with physical or mental disabilities."

Article 132: "Children with special needs, such as disabilities, should benefit from an appropriate support system [in relation to process of transition from care], ensuring, inter alia, avoidance of unnecessary institutionalization."

Other global guidance

Other international guidelines recognize, support and build on these conventions and reinforce their strength as instruments that can be used to ensure compliance and challenge transgression. For example:

Voluntary international agreements also play a part. For example:

The International Committee of the Red Cross and Red Crescent (2004) Inter-agency Guiding Principles on Unaccompanied and Separated Children in emergencies, while not specifying needs of children with disabilities in particular, recommends "... that all actions and decisions taken concerning separated children ... respect the principles of family unity and the best interests of the child. All stages of an emergency are addressed: from preventing separations, to family tracing and reunification, through to interim care and long-term solutions ..."

