## BASIC STUDY ON THE KNOWELDEGE, ATTITIUDES AND PRACTICES OF YOUNG PEOPLE AND ADOLESCENTS WITH DISABILITIES IN TERMS OF SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS (SRHR) IN BURUNDI

### BY

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#### Abstract

People living with disabilities often depend on their living environment for access to knowledge about sexual and reproductive health rights and this knowledge influences sexual attitudes and practices. This exploratory study aims at identifying the level of knowledge, attitudes and practices of young people and adolescents living with disabilities in terms of SRHR in order to advocate for their inclusion in SRHR policies.

Eighteen young people and adolescents including six blind, six physically disabled, two cerebral palsy, one albino and three death-mutes living in different centers, both urban and rural, participated in the study. Using an interview guide with various themes, namely the state of knowledge, attitudes and practices of young people and adolescents living with disabilities in relation to SRHR.

Sexuality education considered taboo in Burundi, lack of policy including the needs of people living with disabilities, lack of manuals specific to the type of disability, the disability situation which limits mobility, lack of training for center staff are identified as barriers to sex education. The results illustrate that these young people and adolescents living with disabilities have limited knowledge about SRHR, which influences the adoption of risky attitudes and practices.

This exploratory study is of capital importance not only for decision-makers but also for other actors and interveners insofar as they will take into account the results on the issue from it, with a view to the full inclusion of all people living with disabilities, in SRHR policies and interventions.

Keywords: sexual health, disability, sexual and reproductive education

### RESUME

Les personnes vivant avec handicap dépendent souvent de leur environnement de vie pour avoir accès à des connaissances en matière de santé et droits sexuels et reproductifs (SDSR), et ces connaissances influencent les attitudes et les pratiques sexuelles. Cette étude exploratoire a pour objectif d'identifier le niveau de connaissances, les attitudes et les pratiques des jeunes et adolescents vivant avec handicap en matière de SDSR afin de faire le plaidoyer pour l'inclusion de ces derniers dans les politiques de SDSR.

Dix-huit jeunes et adolescents dont six aveugles, six handicapés moteurs, deux infirmes moteurs cérébraux, un albinos et trois sourds-muets hébergés dans les différents centres tant urbains que ruraux ont participé à l'étude. A l'aide d'un guide d'entretien comportant divers thèmes, des entretiens semi-structurés ont été menés. L'analyse thématique a tourné autour de trois thèmes généraux, à savoir l'état de connaissances, les attitudes et les pratiques des jeunes et adolescents vivant avec handicap, en matière de SDSR.

Les résultats illustrent que les jeunes et adolescents vivant avec handicap ont des connaissances limitées en matière de SDSR, ce qui influence l'adoption des attitudes et des pratiques sexuelles à risque. Le manque de politique incluant les besoins des personnes vivant avec handicap, le manque des manuels spécifiques au type de handicap, la situation de handicap qui limite la mobilité, le manque de formation pour les personnels des centres sont identifiés comme des obstacles à l'éducation sexuelle. Cette étude exploratoire est d'une grande importance non seulement pour les décideurs mais aussi pour les autres acteurs et intervenants dans la mesure où ils vont tenir compte des résultats qui en sont issus, en vue de l'inclusion totale de toute personne vivant avec handicap dans les politiques et interventions en matière de SDSR.

Les mots clés : santé sexuelle, handicap, éducation sexuelle et reproductive

### Introduction

Sexual and reproductive health and rights (SRHR) constitute an important human factor, whether a person lives with a handicap or not. According to Giami and Toniolo (2013, page 9), to question on human sexuality is to question on mankind. Human development under all forms including human sexual health is facilitated by ability, skills and appropriate behavior acquisition. But different people living with handicap can have insufficient or erroneous in terms sexual and reproductive health and rights. The lack of information on SRHR is a limitation for an individual to acquire better knowledge of their body, better understanding their needs and desire as well as self-awareness. It can also bring about inappropriate sexual whose consequences can be dangerous for the related person and for the family and the society in general.

The aim of this study is to identify the state of mind, the attitudes of youth and adolescents living with handicap in SRHR in order to do advocacy for their inclusion in the SRHR policies. The target population is made of youths and adolescents living with handicap aged between 10 and 24 years, which implies in our understanding, a group of people unconscious about in SRHR to date in Burundi. This study has made us collect qualitative data susceptible to consolidate policies and to improve the interventions in order to respond efficiently to the needs persons living with handicap in SRHR.

Let us mention that this study is in line with Share Net Burundi missions and policies, which is a platform for sharing knowledge about youth sexual health and reproductive rights. Its mission is to improve Burundians sexual and reproductive health through open communication, knowledge share, research facilitation and the advocacy achieved by setting up adjusted health policy.

This work is divided into three parts. The first is about the problematic and the study context about sexuality and reproductive health and rights for persons living with handicap. The second is about the study methodology, the aim of the study and how this study was conducted. The last section presents the results and their discussions as well as relevant recommendations.

### 1. Problematic

Young people and adolescents constitute a heterogeneous group with different and changing needs, depending on their stage of personal development and their living conditions. During the transition from childhood to adolescence and adulthood, everyone will have to acquire the knowledge, skills and strategies necessary to seize the possibilities in order to meet the challenges that will arise in the adult world and especially in sexual and reproductive health and rights (SRHR). In some African countries, including Burundi, sexual health education remains superficial as subjects related to sexuality remain taboo in almost all families; which is at the origin of certain abnormal sexual behaviors including sexual assault, harassment, etc. This emerges from a study carried out in five African countries among "normal" young people and adolescents. The results of this study show that almost all of the young people (aged 18-24) interviewed have been sexually assaulted at least once, and more than once, in their lifetime. Based on a number of studies done on SRHR education, it has been found that knowledge about SRHR does not come from reliable institutions like family, school, churches and communities. 'Other social groups with skills required in the field. Indeed, according to UNFPA (2018), most young people and adolescents have discovered sex and sexuality through television, the Internet, friends and online social networking sites, and all information they received was not necessarily accurate. None of them have received any training or information on gender-based violence, including how to recognize, prevent and respond to it.

As for young people and adolescents with disabilities, should complementary strategies be used to meet the heterogeneous needs of young people and adolescents with special needs, or with disabilities? However, apart from the lack of these complementary strategies, young people and adolescents with disabilities have limited knowledge in terms of sexual and reproductive health, compared to "normal" young people. They do not even have access to certain sources of information (television, internet, limited circles of friends, etc.), and this due to the fact that young people with disabilities, in Burundi as in the whole world, face to persistent social disadvantages stemming from discrimination, stigma and prejudice as well as the continued failure to include disability in the design of policies and programs. Despite this lack of knowledge about SRHR, young people with disabilities engage in sexual activities in the same way as young people without disabilities and they have the same concerns, needs and rights regarding sexual and reproductive health, including sexuality, access to contraceptive services and family planning. The low level of education in SRHR, among other related rights, prevention and transmission of sexually transmitted diseases, management of the menstrual period, contraceptive methods, and management of the pubertal and adolescent stages, violence based on gender, the existence of health and education services intervening in this area can lead to dangerous sexual behavior. Studies have shown that adolescents with disabilities are part of a low rate of condom use and contraception, but they participate in free or transactional sex acts. In addition, HIV testing is lower among young people with disabilities, even though they are at the same or higher risk of contracting sexually transmitted diseases than their non-disabled counterparts.

This lack of information and sex education means that young people and adolescents in seeking to satisfy their sexual curiosity encounter problems which they could have avoided if the information had been given through appropriate channels. Among these problems we can cite STIs / HIV, early marriages and pregnancies, unwanted pregnancies and no safe abortion with the all consequences on the health of the future mothers.

In a study realized by the African Child Policy Forum on violence against children with disabilities, almost all young people (aged between 18 and 24) who were interviewed had been sexually assaulted at least once, and most more than once, in their lifetime (The African Child Policy Forum, 2010). In the same ideal order, another study shows that children with disabilities are also four times more likely to be victims of violence than children without disabilities, and three times more likely to experience sexual violence (UNFPA, 2018).

For everyone's well-being, the international community through the Sustainable Development Goals is committed to leaving no one behind. In order for this commitment to become a reality for young people with disabilities, governments must invest in young people and ensure that young people with disabilities have the opportunities, knowledge and skills to live healthy, fulfilling and productive lives. In this perspective, there are a number of legal texts, both national and international, which recognize the importance of sexual and reproductive health rights (DSSR), in particular the law promoting and protecting the rights of persons with disabilities in Burundi, the International pact Convention on Economic, Social and Cultural Rights (art. 12), the Convention on the Elimination of All Forms of Discrimination against Women (art. 12), the Convention on the Rights of the Child (art. 17, 23–25 and 27), the Convention on the Rights (arts. 12, 23 and 25) and other legal texts. It should be emphasized that sexual and reproductive health rights are not only an

integral part of the right to health, but they are also necessary for the enjoyment of many other human rights.

As a result, rights related to sexual and reproductive health are universal and inalienable, indivisible, interdependent and interrelated (United Nations, 2017).

Aware of the problem, the Government of Burundi through the National Reproductive Health Program (PNSR) has initiated a number of SRHR activities adapted to young people and adolescents to meet the needs of young people and adolescents in terms of SDSR. By way of illustration, we can cite the creation of youth centers, "Stop AIDS" clubs in secondary schools as well as the establishment of youth-friendly health centers.

It should be noted that the knowledge products developed by PNSR do not take into account the needs of young people and adolescents with disabilities, neither in the training of workers from the various services, nor in the design of manuals and teaching materials. Adapted to the specificity of each disability due to the fact that young people and adolescents with disabilities are part of the marginalized and discriminated categories in Burundi in general and in particular with regard to the SRHR. This failure to take into account the specific needs of young people and adolescents with disabilities means that they have insufficient information on SRHR, which leads to dangerous attitudes and practices. To cope with this situation, schooling is one of the means to access education in SRHR; but alas, young people and adolescents with disabilities are often the least likely to attend school.

Note that the PNSR is supported in its programs by a number of national and international partners such as PSI, PMC, Care International Burundi, Rutgers, UNFPA, GIZ as well as Share Net International via its branch in Burundi. This study is in line with the objectives of Share Net Burundi. This is a knowledge-sharing platform on Sexual and Reproductive Health and Rights, since June 2016, which focuses on young people and adolescents. Its mission is to improve the sexual and reproductive health of Burundians through open communication, knowledge sharing, facilitation of research and advocacy through the implementation of an appropriate health policy. Share Net Burundi deals with various themes, the most important of which are research on sexual and reproductive health and rights targeting both school-going and out-of-school youth, access to health services and sexual and reproductive rights such as maternal care and family planning, socio cultural opportunities and barriers to sexual and reproductive health and rights, knowledge, attitudes and practices among different demographic groups, community involvement in the area of sexual and reproductive health

and rights including efforts faiths and civil society, integration of sexual and reproductive health and rights programs into performance-based financing, research for the development of a comprehensive monitoring and evaluation system for sexual and reproductive health and rights programs and focused on young people. In the case of this study, the objectives relate to the SRHR of young people and adolescents with disabilities.

### 2. Study objectives

The general objective of this study is to identify the level of knowledge, attitudes and practices of young people and adolescents with disabilities regarding SRHR in order to advocate for their inclusion in SRHR policies. As for the specific objectives, it is a question of identifying the level of knowledge of young people and adolescents with disabilities in SRHR, to identify the attitudes of young people and adolescents with disabilities on the use of contraceptive methods and the fight against STDs and to discover the practices of young people and adolescents with disabilities as well as the violence to which they are subjected in terms of SRHR.

Identifying the knowledge, attitudes and practices of young people and adolescents regarding SRHR will result in an article, which will facilitate their advocacy in improving policy practices. This will inform the Ministry in charge of human rights and gender equality, the PNSR and all programs to combat stigma and discrimination against vulnerable minorities, particularly young people and adolescents with disabilities. The results of this study will make it possible to carry out concrete activities for their full inclusion in the field of SRHR.

### 3. Methodology

This study is fundamental and exploratory because it aims to acquire new knowledge likely to contribute to the advancement of scientific knowledge. To arrive at the results of this study, data collection was carried out through semi-structured interviews with young people and adolescents with disabilities using an interview guide. This interview guide has a number of topics relevant to the topic under study. In order to obtain additional information, a questionnaire aimed at the SWIFT analysis was distributed to the managers of the centers which were the subject of an investigation. In addition, consultations with stakeholders in SRHR were conducted.

Before collecting the data in the field, we did the documentary research to assess the state of existing theoretical knowledge in the field of SRHR. In addition to this documentary research, we mapped the centers housing young people and adolescents with disabilities; which allowed us to select two centers that were investigated according to a number of criteria. Among these criteria, we have retained the location of the center (urban-rural) as well as the gender criterion. The interviews based on as many themes focused on three areas of investigation:

1) Level of knowledge of young people and adolescents with disabilities in terms of SRHR,

2) Attitudes of young people and adolescents with disabilities in regard to SRHR and

3) Practices of young people and adolescents with disabilities and the violence they suffer in terms of SRHR.

In each center, we interviewed young people and adolescents of both sexes between the ages of 10 and 24. The choice of respondents was also motivated by seniority at the center of at least one year. We then spoke with the managers of the centers to find out about the opportunities, threats and obstacles of their center in terms of SRHR. In these interviews, apart from taking notes, we used a recording device to keep all the information. Taking into account the types of disability, we used the interpreter to facilitate communication. Afterwards, we moved on to the stage of transcribing the contents of the interviews before moving on to the stage of discussion, and this was done topic by topic according to each objective.

### 4. Results and Discussion

The data analysis focuses on three general themes: the level of knowledge of youth and adolescents with disabilities regarding sexual and reproductive health and rights (1), attitudes of youth and adolescents with disabilities regarding SRHR (2), practices of youth and adolescents with disabilities and the violence they experience regarding SRHR (3). Some of the participants' comments are mentioned to illustrate their knowledge, attitudes and practices.

## 4.1. Level of knowledge of young people and adolescents living with disabilities regarding sexual and reproductive health and rights

### a. Secondary sexual characteristics and menstrual cycle

Before talking about secondary sexual characteristics and the menstrual cycle, we wanted to know what our respondents understood by SRHR. The answers given by the respondents show that most of them are not familiar with this topic. There are also those who confuse it with other themes and others who partially explain it. For G010, when we talk about sexual and reproductive health and rights, we mean human development with good health. For G022, when we talk about SRHR, it includes living well, eating well and being well cared for. For G011, it is birth spacing and family planning within the means available. In the comments, some youth and adolescents living with disabilities think that SRHR is only for married people. For them, they only need information that will be useful once they are married. This is reflected in G020's comment: "Kuri jewe nk'umuyabaga, ntahura ko dukeneye inyigisho zijanye n'amagara n'uburenganzira mu vyerekeye irondoka n'uguhuza ibitsina kugira tumenye uko tuzokwitwara tumaze kubaka. This translates as follows: "for us young people, I understand that we need information about SRHR, so that we know how we will behave when we are married".

In terms of secondary sexual characteristics, the subjects mentioned the development of breasts in girls and the onset of the first menstrual period, as well as the development of the pelvis. For the boy, they evoke the modulated voice, the appearance of the beard as well as the porosity, the shoulders which become broad. Others mention the appearance of pimples on the face and the maturity of the spermatozoa and the development of the buttocks as well as the appearance of ideas related to sexual relations. We find that the majority of young people and adolescents with disabilities do not know all the secondary sexual characteristics; some identify only one, two or three characteristics.

When asked about the beginning of the menstrual cycle, some respondents pointed to the day of menstruation and others thought it began on the 14th day after menstruation. Nevertheless, there are others, especially males, who do not know. As for the period of ovulation and fertility, it appears that these young people and adolescents living with disabilities do not master it. The majority of them are aware of this during their menstrual periods. However, only two cases, like CND027, have a good grasp of this. As for the source of this knowledge, the interviewees mentioned the following sources: community leaders, radio, school/center,

stop AIDS clubs, educators, family members, peers and seminars mentioned by one case. It should be noted that peers were cited by most of the young people and adolescents living with disabilities as their source of information, which explains why the information they have is almost incomplete or incorrect.

### b. Contraceptive methods and gender-based violence

The most frequently mentioned contraceptive methods are abstinence, safe sex (use of condoms), pills, contraceptive implants, IUDs, combined injectable contraceptives and the natural method (calendar). CND027 also emphasizes regular breastfeeding for women. At the end of the interviews, we found that no respondent was aware of all the contraceptive methods.

For methods of prevention against sexually transmitted diseases (STDs), some subjects mention avoiding unnecessary communication with others of the opposite sex, using condoms, abstinence and not watching pornographic films. The importance of knowing the contraceptive methods mentioned is to prevent unwanted pregnancies and sexually transmitted diseases.

Regarding the harmful consequences of these methods, some subjects emphasized the fact of becoming sick, losing weight, swelling of the body, gaining weight, difficulties in removing the used material (IUD, contraceptive implant), sterility, complete disappearance of menstruation, giving birth to a child with a disability, having cancer of the uterus. For others, using these methods is a sin, and they are not 100% effective because sometimes one can conceive during planning. It should be noted that there are others who are not aware of any of these consequences.

Almost all the respondents believe that contraceptive and STD prevention methods are necessary for young people and adolescents living with disabilities, because they say: "We are like other able-bodied young people", others do not consider this important (case of CND027) and some subjects hesitate about this importance. This is what N012 said: "Jewe ku bwanje numva umenga bwokoresha abubatse. Mugabo n'imiyabaga igendana ubumuga barashobora kubukoresha kuko nabo nyene barashobora gukora imibonano mpuzabitsina. This translates as follows: "According to me, I believe that these methods could be used by the married couple. However, even young people and adolescents living with disabilities may need them because they can also practice sexual intercourse.

The survey showed that these methods are not available in the centers we studied. However, the importance of the availability of these methods was reported by almost all the respondents. Given that some centers are managed by religious denominations, their managers emphasize that it is not permitted to make these methods available to these young people because, according to them, they would push them to adopt sexual behaviors that do not conform to their beliefs. Therefore, they advocate abstinence as a means to fight against unwanted pregnancies and sexually transmitted diseases.

As for the period during which a girl/woman is most exposed to pregnancy when she has unprotected sex, many respondents do not have sufficient knowledge on this point and therefore do not know how to prevent unwanted pregnancies. Some of them find that they are most at risk during their menstrual periods. On this subject, N011 expresses oneself as follows: "igihe co gusama imbanyi ni iyo ukoze imibonano mpuzabitsina umusi imbere y'uko uja mu butinyanka; canke imisi ibiri imbere yaho". This translates as follows: "Conception can occur when one has sex the day before or two days before the menstrual period.

Almost all of our respondents were unaware of gender-based violence. Also, some of our respondents confuse gender-based violence with discrimination. For example, GO20 cited the fact that a daughter does not inherit land from her parents in the same way as her brother. Among those who have any idea about gender-based violence, they point only to rape and torture of women who give birth to female children.

### c. Knowledge about HIV and STIs and how to prevent them

Almost all the young people and adolescents surveyed had already heard about HIV/AIDS. The means of contamination mentioned are unprotected sexual intercourse, sharp tools already used by the HIV-positive, kissing when there are wounds on the lips and tongue, and mother-child transmission. Regarding their means of prevention, the respondents returned to abstinence, avoiding unprotected sex, avoiding the use of sharp tools already used by others. Some respondents have erroneous information about the means of prevention of sexually transmitted diseases, such as G021, who stresses that a circumcised boy cannot be infected by the virus. We note that some of our respondents do not advise their peers to use condoms to prevent HIV/AIDS. As mentioned above, they always emphasize abstinence as the only effective way to prevent HIV/AIDS.

As for the means of transmission of sexually transmitted infections, we note from their responses that these children living with disabilities are not familiar with them. They are unable to list all the ways in which they transmit sexually transmitted infections, and many can only mention one way. G011 said that when one goes to the toilet after someone else with STIs, one can catch them when they have not cleaned the toilet. The results of this study show that these children living with disabilities are not aware of all STIs and others confuse them with other diseases. As for other infections, gonorrhea, syphilis, hepatitis C and shingles were mentioned. However, there are others who are confused, for example G020 who mentions vaginal fistulas as an STI.

### d. Sources of Knowledge

A small number of young people and adolescents living with disabilities emphasize that their father or mother is a reliable source of information about SRHR, and others mention their brothers and sisters. However, we find a few respondents who indicate that no family member gives them information about SRHR. In almost all centers, staff are a reliable source, but do not facilitate access to SRHR-related information when necessary.

Some of our respondents revealed that facility staff do not readily give them information about SRHR because it would encourage them to engage in sex that is prohibited in all shelters. However, according to a study conducted for Ending Gender-Based Violence and Enforcing Sexual and Reproductive Health Rights, there is no evidence that comprehensive sexuality education increases sexual activity, sexual risk-taking, or rates of HIV infection or other STIs (source). Yet comprehensive sexuality education in schools has also been shown to be a cost-effective intervention that contributes to HIV prevention. It should be noted that peers facilitate access to SRHR information. However, the information shared is not reliable and revolves around sex only. Others, finally, point to community facilitators as a reliable source that facilitates access to SRHR-related information when needed, especially during vacations.

Regarding the most preferred source of information about SRHR, some mentioned their elders, others mentioned the center's educators, radio, television, community leaders, and other youth. Only GO22 cited the father as the most important source of information. This shows that sexuality remains a taboo subject in the Burundian context, because parents, who should be a reliable source, are unfortunately not considered by their children. This finding was also mentioned in the final report of the Joint Program for the Improvement of Sexual

and Reproductive Health of Adolescents and Youth aged 10-24 years in Burundi (2017), where only 11.4% of adolescents and youth (10-24 years) confirm that their family supports their access to sexual and reproductive health information and services for adolescents and youth.

It is also worth mentioning that there are no sessions dedicated to sexuality education in the centers surveyed. As for the existence and importance of stop AIDS Clubs, almost all the respondents said that there were none.Nevertheless, they stressed their importance. They felt that these stop AIDS clubs would be a source of information about SRHR. Regarding the existence and accessibility of youth-friendly health centers, many of our respondents were not aware of their existence and the services they offer, except in a few cases, such as GO21, who emphasized that they are of paramount importance in providing reliable knowledge about SRHR and in making contraceptive methods available

### 4.2. Attitudes of youth and adolescents living with disabilities towards SRHR

Some of the young people interviewed emphasized the importance of education on SRHR at the center and/or at home in order to adopt responsible behavior in their daily lives. This education allows them to avoid unwanted pregnancies but also to avoid risky sexual behavior. Moreover, these young people find that when they are trained, they will in turn train other young people; this training will also be very useful in their marital life.

Regarding the attitude displayed by these young people when they feel a sexual need, they mention abstinence, prayer, and looking for another activity to replace this idea in their minds. A few rare cases, such as N023, point out that they may seek to satisfy this need by using condoms. As for the attitudes displayed when they are asked to have sex, some young people and adolescents living with disabilities emphasize that they refuse the request, explaining the harmful consequences that may result from it, while others emphasize that they categorically refuse and put aside those who want to try it. Nevertheless, there are others who say that they accept to have sex, but with condoms. In case of concern about how to behave in SRHR, some young people and teenagers with disabilities' consult the professionals in charge and others do not. The people often consulted are: educators, community leaders when they are at home. There are others who do not see where to go and seek advice from their peers; and others who want to consult but are unable to because of their disability. G021 puts it this way: "Biragoye kuronka uwo witura muri kino kigo; ntidushobora gushika ahariho hose

tudafashijwe kubera ubumuga tugendana. Niyo dusavye uruhusha ngo tuje kw'ivuriro canke ahandi hantu tworonkera inyishu ku makenga mu bijanye n'amagara n'uburenganzira mu vyerekeye irondoka n'uguhuza ibitsina, ntibatwemerera, batubwira ko bitihutirwa". This translates as follows: "It is difficult to find someone to consult at the center, we do not move around without help because of our disability. We are not easily given permission to go to the health center or to another place to get reliable answers regarding SRHR concerns, because we are told that it is not very urgent''. Few of those surveyed had ever consulted a service for reliable information. In case of consultation, the reasons given were, among others, problems of infection in the genital organ and lack of understanding of the menstrual cycle in girls.

As for the importance of getting tested for HIV and STIs, our subjects mention the desire to know their serological status. This is how respondents N010 and GO20 expressed themselves: "Ni vyiza kwipimisha kugira umenye amagara yawe, wirinde kwanduza abandi". This translates into: "It is important to get tested to know one's HIV status and thus avoid infecting others. As for the role of young people and adolescents living with disabilities in the fight against unwanted pregnancies and sexually transmitted diseases, they emphasize the advice they give in order to avoid risky sexual practices and to make young people aware of the negative consequences of unwanted pregnancies and sexually transmitted diseases. It should be noted that some of these young people and adolescents do not know their role in the fight against unwanted pregnancies and sexually transmitted diseases.

When asked whether the views of youth and adolescents living with disabilities are integrated into SRHR policies, the majority of our respondents felt that their views are not integrated. Some, like G021, say they do not even find an opportunity to express themselves. "Our ideas stay inside ourselves," he said. They even manage to imagine that it would be discrimination compared to "normal" youth. This is reflected in the words of N012: "Ngira baca bibaza ko abagendana ubumuga bitabaraba, bakabifata minenerwe". Which translates: "Maybe they think that youth and adolescents with disabilities are not concerned and do not take our views seriously". In order to improve these policies, youth and adolescents living with disabilities request that they be given opportunities to express their views on SRHR. Awareness sessions on the fight against unwanted pregnancies, HIV/AIDS and other STIs should be organized for them. They also request full inclusion in the development and changes of SRHR policies.

## 4.3. Practices of young people and adolescents with disabilities and the violence they experience regarding SRHR

To learn about SRHR, some young people and adolescents with disabilities ask their parents, their peers, their elders, their educators, and the radio/television. However, others say that they do almost nothing to benefit from it. They just wait for those who would go to educate them. In order to avoid being infected with HIV/AIDS and STIs, most of the respondents say they practice abstinence; a minority confessed that they practice condom sex. Others avoid using sharp tools used by others, avoid long conversations with people of the opposite sex, and avoid going out alone at night. Almost all youth and adolescents have already been tested for HIV/AIDS, but there are others who have not yet been tested. Among the reasons mentioned, there is the obligation of the center to be tested in order to know the serological status of these young people and teenagers as well as voluntary testing for some rare cases.

As for sanitary napkins, some young adolescents in the centers surveyed could not find them easily and resorted mainly to using pieces of cloth that do not facilitate cleanliness, such as cotex sanitary paper. Respondent CND020 added that when she does not have these toilet papers or pieces of cloth, she manages to wash herself most often. To protect themselves and others from unwanted pregnancies, some young people counsel each other, avoid cronyism or refuse to have relations with dubious people, use condoms and pills, and avoid going out or being alone at night. To protect themselves from sexual violence, these youth say they follow the advice they are given about SRHR. Others refuse gifts from people who want to take advantage of their vulnerability.

Regarding the sexual practices that can be identified among youth with disabilities, most of them are not aware of them. However, some practices were highlighted in some of the centers such as masturbation, rape, homosexuality, harassment, watching pornographic movies, prolonged kissing as well as touching. This is supported by Giami &Toniolo (2013) who believe that some people in institutions attend some forms of possible sexual life such as the use of pornography and the use of masturbation. To their knowledge, it is not excluded that these young people and adolescents with disabilities may resort to similar practices and/or attitudes. This question showed us that these young people and adolescents living with disabilities have difficulty talking about sexuality; they answer with difficulty and shame

without even looking at the interviewer. They emphasize that the information they give comes from other young people.

In the case of concerns about the consequences of their behavior, the professionals consulted included educators at the center, parents at home and community leaders. In the case of the harassment that occurred, CND023 went to the police and the administrator of her community when she was threatened with rape. She ended up moving from where she was living to protect herself from this person. They affirm the implementation of the advice given. As these young people have difficulty moving because of their disability, we note that they consult the people close to them, which means that health professionals are not mentioned. It should be noted that those who said they had consulted put the advice given into practice.

Some of these children with disabilities feel that they are discriminated against. They see this in their environment and at school. As N011 says: "Birashika bakadukumira. Mukoze urubanza i muhira bakavuga ngo urya ntaco ashoboye canke bakakunyegeza ngo ntibakubone. This translates into: "Sometimes they discriminate against us. When we organize a family party, we say that a child living with a disability is not capable of anything or we may hide you so that others do not see you. This discrimination was also mentioned by CND020 who expressed oneself as follows: "Bahora bankumira ngo ntitwosangira, ntitworyamana ng'aha kwishule". This translates into: "I am being discriminated against by saying that we could not eat together or sleep together".

To avoid discrimination, they advise each other to get together with their "able-bodied" peers and act to show that they are like others and capable of certain tasks. At this point, G011 expresses oneself as follows: "Turabatahuza ko umuntu afise ubumuga ameze nk'abandi, ashoboye ibikorwa nk'abandi". This translates into: "We make them understand that a person living with a disability is a person like many others, capable like others". For G012, "kugira twirinde ikumirwa, abafise abana bagendana ubumuga boreka kubanyegeza, bakabashira ahabona kuko na bo ari abana nk'abandi. This translates into: "To avoid discrimination, those who have children with disabilities, would avoid hiding them, but leave them with the others because they are also children like the others". This is also the case of CND022 who thinks that people should understand them because they have not contributed anything to find themselves in the state they are in. These young people emphasize that they do not discriminate against others. They ask for sensitization for them and for able-bodied people to make them understand that they are like other people.

### CONCLUSION

Sexual rights are plural and their application to people with disabilities must be guaranteed as well as adapted to the disability situation. These rights guarantee the freedom of sexuality for everyone, as defined by the World Health Organization (WHO). We have seen that non-discrimination and the prohibition of violence are important components, as well as access to health and education services. The purpose of this study was to identify the knowledge, attitudes, and practices of youth and adolescents regarding sexual and reproductive health and rights. Data were collected through semi-structured interviews.

The analysis of the results of this study allows us to note that there are still many barriers limiting the access of people living with disabilities to knowledge about SRHR, which influences their attitudes and practices. In fact, parents and educators, who should play a fundamental role in sexuality education, are not a reliable source for the young adolescents living with disabilities who were the subject of our study. They have knowledge that generally comes from exchanges with their peers, which means that some of their knowledge is erroneous. This knowledge causes these young people and adolescents living with disabilities to adopt risky sexual attitudes and practices, which may even be the cause of the sexual and physical abuse they are often subjected to.

We believe that this basic study on the knowledge, attitudes and practices of young people and adolescents with disabilities reflects a fairly real problem, and the resulting knowledge product will help decision-makers develop and change sexual and reproductive health and rights (SRHR) policies in Burundi. These results will also inspire SRHR workers for this specific population, center and school officials, and parents. It is important that the sexual needs of people living with disabilities are considered and discussed rather than avoided or ignored due to lack of knowledge or clear guidelines. In light of this study, future research can focus on identifying the real needs of people living with disabilities in relation to SRHR, taking into account their immediate environment, in order to fully include them in policies related to sexuality education. In addition, we believe that it is important to conduct another study to know the state of knowledge of young people and adolescents who have not attended centers and/or schools.

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## ANNEXES

## Guide d'entretien

## 0. Consigne en Kirundi

Mwaramutse,

Nitwa.....

Turiko turagira icigwa c'ibanze kijanye no kumenya urugero uwaruka rugendana ubumuga rufise mu vyerekeye ubumenyi, inyifato, imigenzo n'imigirwa mu kubijanye n'uburenganzira bwo guhuza ibitsina n'amagara meza. Iki cirwa casabwe n'ishirahamwe Share Net Burundi kizofasha cane kumenya urugezo rw'ubumenyi mu rwaruka rugendana ubumuga kugirango ruzofatirweko mu mugambi w'Igihugu w'ironderondoka rijanye n'amagara meza, hamwe n'amashirahamwe ashigikira uyo mugambi. Iki cigwa kizofasha kandi Abaharanira agateka k'Abana n'imiyabaga bagendana ubumuga kugira bagire uburenganzira nk'ubwo abandi bana bose bafise mu vyerekeye irondoka rijanye n'amagara meza. Nari nipfuza rero kuyaga nawe bimwe bimwe mu vyerekeye irondoka rijanye n'amagara meza muri rusangi, kandi kugira ngumane ivyo tuganira vyose, ndakoresha akuma kabika amajwi nongere nandike. Inyishu yose uza kuyitanga uko ubitahura. Ico udatahura ntakibazo uraza kumbaza nkutahuze. Mu kiyago tuza kugiranira, nta muntu wundi azomenya ivyo twaganiriye ; nta n'uwuzomenya uwo twaganiriye.

Niwaba ufise ikibazo ku vyerekeye iki cirwa, urashobora kukimbaza imbere yo gutangura. Iki kiganiro kiza kumara iminota mirongo ine n'itanu.

Mbaye ndagushimira ko wemeye iki kiganiro.

### **Interview guide**

Luggage storage in English

Hello,

My name is .....

We are currently carrying out a baseline study on the knowledge, attitudes and practices of young people and adolescents with disabilities in matters of Sexual and Reproductive Health and Rights (SRHR) in Burundi. This study commissioned by Share Net Burundi will identify the level of knowledge of young people and adolescents living with disabilities in order to integrate their points of view into national policies and programs related to SRHR, as well as those of NGOs involved in this domain. This study will also allow activists for the rights of people with disabilities in general and those of young people and adolescents in particular to advocate so that they have the same rights and freedoms as other young people and adolescents with regard to SRHR. So I would like to discuss with you some aspects related to SRHR in general and in order to keep all the content of this interview, I use the recording device and I take note of the essential elements. I guarantee your anonymity when analyzing and publishing the results.

You have the right to ask me any question if you don't understand. If you have any questions before starting this interview, you can ask them. This interview will last 45 minutes at most. My anticipated thanks.

## Theme 1: Level of knowledge of young people and adolescents with disabilities in SRHR

## 1.1. Secondary sex characteristics and the menstrual cycle

- What are the secondary sex characteristics? When does the menstrual cycle begin?
- Are you in control of your ovulation and fertility period? How did you know about this?

## 1.2. Contraceptive methods

- What methods of contraception do you know?
- How important are contraceptive methods?
- When is a girl / woman most at risk of pregnancy when having unprotected sex?
- Are you aware of GBV)? If so why?

## **1.3.** Knowledge of HIV and the means of prevention?

- Have you ever heard of HIV AIDS)? Means of contamination)
- What are its means of prevention)?
- Do you ever advise your friends to use condoms to prevent HIV / AIDS?

## **1.4. Knowledge of STIs**)

- Have you heard of STIs)?
- Its means of transmission)?
- Do you know how to prevent STIs)?

## **1.5. Source of knowledge)**

- Which family member is a reliable source and facilitates access to information related to SRHR, if applicable?
- Do you think that the staff of the center constitute a reliable source and facilitate? If necessary, access to information related to SRHR?
- Do you think that your peers are a reliable source and facilitate access to information related to SRHR where necessary?
- What is the source that you favor the most for information relating to SRHR?
- Are the stop AIDS clubs available or not? Are you aware of the existence and accessibility of youth-friendly health centers and the services offered (information, condom supply, screening, treatment of SGBV, FP, pre- and post-natal consultation, childbirth, vaccination, etc.)
- Are you aware of other sources of SRHR information in your home setting? (Community animators)

- Are you aware of national and international legal texts for the promotion and protection of SRHR? (Which ones)? Do you find that they are respected in the center and in the neighbourhood?

# Theme 2: Attitudes of young people and adolescents with disabilities in relation to SRHR)

- Do you find it important to have SRHR education at the center and / or at home?
- Do you find it important to provide young people and adolescents with disabilities with means of preventing STDs and unwanted pregnancies?
- When you happen to feel a need for sex, what attitude do you adopt?
- When you are asked to have sex, what behavior do you show?
- When you have concerns about the behavior to adopt in SRHR, have you had the idea to consult one of its services?
- For which motive?
- Do you find it important to be tested for HIV and STIs)?
- Do you find that the views of young people and adolescents living with disabilities are integrated into SRHR policies?
- What do you propose to improve these policies)?

# Theme 3: Practices of young people and adolescents with disabilities and the violence they suffer in relation to SRHR

- What do you do personally to have knowledge of SRHR?
- What do you do personally to avoid getting infected with the AIDS virus and STIs?
- Have you ever been tested for HIV / AIDS? If so, for what reason?
- Do you use sanitary napkins and are they readily available to you?
- In case of unavailability, what means do you use?
- What are you doing to protect yourself and others from unwanted pregnancies?
- What are you doing to protect yourself against sexual violence?
- What are the identifiable sexual practices among young disabled people (masturbation, porn, homosexuality, harassment, etc.)?
- In case of concerns related to the behaviors adopted (unprotected sex, sexual violence, harassment, masturbation etc.) which service did you consult?
- If you have consulted the SRHR services, have you put into practice the advice given