ASSESSMENT OF PREVAILING KAPs & SOCIAL NORMS TOWARDS CHILDREN AND ADOLESCENTS WITH DISABILITIES IN RWANDA AND THEIR ACCESS TO AN INCLUSIVE EDUCATION AND THE ABILITY TO GROW AND DEVELOP IN A FAMILY ENVIRONMENT

Formative Research
RESEARCH METHODOLOGY

- Research methodology draws upon the International Classification of Functioning, Disability and Health (ICF), operational research protocol and a monitoring and evaluation (M&E) framework developed by Drexel University and the UNICEF Europe and Central Asia Regional Office.

- Research protocol and M&E framework were developed to measure changes in discriminatory attitudes and social norms regarding children and adolescents with disabilities.

- The CRPD definition of disability guides the research inquiry, namely “long-term physical, mental, intellectual, or sensory impairment, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Article 1, 2006).

- Convergent mixed methods design was used in the research, with quantitative and qualitative data gathered simultaneously.

- QUAL and QUAN data were gathered to compliment each other and were merged in the analysis.
RESEARCH QUESTIONS

This formative research was guided by the following questions:

• What are the prevailing knowledge, attitudes, and practices towards children and adolescents with disabilities in Rwanda?
  • How are children and people with disabilities identified?
  • How are children and people with disabilities perceived in Rwanda?
  • What are the prevailing attitudes of Rwandans toward educating children and adolescents with disabilities?

• What are the prevailing attitudes and social norms (including gender norms) Rwandans practice that enable or hinder children and adolescents with disabilities to participate in their communities and public at large, and to exercise their rights to education, health care, and to grow and develop in their family environment?
  • What are the social, including gender norms around child abandonment?
  • What are the social, including gender norms around inclusive education?

• What forms of stigma toward children and adolescents with disabilities are common, and what is their impact on the lives of children and adolescents with disabilities (i.e. social distance between children and adolescents with disabilities and people without disabilities)?

• How do reference networks impact people’s behavior towards children and adolescents with disabilities?

• How can UNICEF and its partners address the needs and challenges faced by children, and adolescents with disabilities?
  • What are the gaps in KAPs, social norms and behaviors that need to be addressed by the communication campaign?
  • What are the gender stereotypes in KAPs towards boys and girls with disabilities that need to be addressed?
The Interactive Voice Response (IVR) survey was administered by VIAMO between 28th September to 5th October 2021 and consisted of 27 questions. The survey was sent to a database of 4,000 mobile numbers in Rwanda and 1,675 successfully completed the survey. The numbers were randomly selected from the Viamo database of more than 805,000 mobile numbers. Stratified random sampling ensured a representative sample and included 50% men and 50% women among the adult population from across urban and rural areas.
FOCUS GROUP DISCUSSIONS WITH ADULT PARTICIPANTS

113 adults (26 Males and 87 Females) from 5 districts, Kicukiro, Musanze, Kayonza, Huye and Karongi participated in 14 focus group discussions. Participants were divided into three groups: (1) parents of children with disabilities, (2) parents of children without disabilities and (3) professionals.
FOCUS GROUP DISCUSSIONS WITH CHILDREN WITH AND WITHOUT DISABILITIES

80 children (41 girls and 39 boys) between 12 and 18 years old from 5 districts, Kicukiro, Musanze, Kayonza, Huye and Karongi participated in 10 FGDs. Children were divided into two groups: (1) children with disabilities and (2) children without disabilities.
22 in-depth interviews were conducted in five study districts. 13 males and 9 females from various backgrounds (teachers, ECD coordinators among others) shared their opinion on the existing KAPs and social norms around children with disabilities.
Key findings of 2021 SBC survey

1,675 respondents through VIAMO

81.6% of respondents think the best place for a child with disability is an institution, whereas ~7.5% think s/he should live at home

79.6% reported to ‘Agree’ that children with disabilities need special institutions to live in

42.8% of respondents reported to ‘Agree’ with the statement that “The majority of families in your community that have a child or children with disabilities try to hide them”

51.9% of respondents reported to ‘Agree’ with the statement that “The majority of families in your community that have a child or children with disabilities are ashamed of him or her”
Key findings of 2021 SBC survey

1,675 respondents through VIAMO

- 48.7% reported they would take their decision regarding their child with disability depending on what other people in their community think
- 47% of respondents, reported to have heard information on children with disabilities on TV and Radio
- 60.3% of respondents reported that boys and girls with disabilities should get equal treatment

*The baseline data show no difference in data across both genders*
WHAT ARE THE PREVAILING KNOWLEDGE, ATTITUDES, AND PRACTICES TOWARDS CHILDREN AND ADOLESCENTS WITH DISABILITIES IN RWANDA?

- Child with disability (CWD) was defined by many study participants as a needy child. A child who is “not like others, who misses some organs” and has “malfuctioning of some parts of the body” (KII).
- Few mentioned that CWD is “a child like others but has significant problems with communication, comprehension, vision, hearing and physical functioning”… “He/She is a child with limited capacity of functioning compared to other children” (KII).
- Some mentioned that CWD may have ”different mindset from others” and he/she cannot do what others without disabilities do (KII).
- Many FGD participants perceive CWD as withdrawn (69%), insecure (44.6%), dependent (31.3%) and negative (31%)
When asked about the types of disabilities, many participants reported that they did not think of physical, sensory, mental and intellectual impairments as disabilities. Moreover, majority of the respondents did not consider sensory impairment as a disability or knew much about mental impairment. The analysis of responses by gender and residence did not produce significant changes in participants’ responses.
The majority of participants across FGDs, interviews and Survey, referred to a CWD as a child who needs support and medical treatment – “CWDs are sick, if medical care is ensured, they can be like others”.

The majority, regardless of their gender and education viewed CWD within the charity model. They felt pity for those with disabilities, and their parents. Referred to CWD as a “problem” and “burden”.

Overall, 58% of male FGD participants and 60% of female participants believed that CWD needs help of others to survive, and only few mentioned that CWD is a child like others with the same rights. Many children participants when asked about the similarities between children with and without disabilities spoke about the same basic rights that children with and without disabilities have, to include their right to live, to eat, to drink and to grow in the family – “We are both given birth to, we both need parental care”.

One of the participants of FGDs became emotional during the discussion while stating “You feel emotion.. You have mercy on him for not being able to perform this and that because of the disability he has…”
HOW ARE CHILDREN AND PEOPLE WITH DISABILITIES PERCEIVED IN RWANDA?

• Some study participants referred to CWDs as a shame. “He/she is not the same as those without disabilities/ He is disturbing” stated one participant. Many wondered about the reasons for their disabilities and their future, with few stating that there is “no hope for children with disabilities”.

• One of the participants, a parent of a child without disability, said that when she sees a child with a disability, she “fears to go out in order to avoid meeting him/her again”.

• Many described children with disabilities as sad and unhappy and few reported that parents hide children with disabilities at homes.
HOW ARE CHILDREN WITH DISABILITIES PERCEIVED BY THEIR PARENTS AND OTHER ADULTS?

• FGD findings showed that parents of CWDs had a more defeatist opinion of CWD as compared to parents of children without disabilities or a group of professionals. Parents believe that CWD are dependent (50%), fearful (46.7%), insecure (48%) and withdrawn (77%), with few of them thinking of a CWD as a positive (8.5%), hardworking (6.4%), and social (8.5%).

• Parents of children without disabilities referred often to both, child with and without disability, as brave (45%), hardworking (63%), and positive (47%). However, overall, parents of children without disabilities attributed often negative adjectives to CWD (ex. negative - 2.6% - child without disabilities, 37% - CWD) and positive adjectives to children without disabilities (ex. cheerful – 48% - child without disability, and 5.3% - CWD) (see the following slide for more detailed data).

• Other FGDs participants, to include ECD specialists, teachers, NCPD Coordinators among others, also projected more positive attitudes to both, children with and without disabilities. For example, they reported that children with and without disabilities are cheerful (78.6%), hardworking (71.4%) and social (75%), lazy (67.9%) and fearful (60.7%). Many of them, however, mentioned that CWDs are withdrawn (57%).
HOW ARE CHILDREN AND PEOPLE WITH DISABILITIES IDENTIFIED BY PARENTS OF CHILDREN WITH AND WITHOUT DISABILITIES?
THE EFFECTS OF SOCIAL NORMS, PEER AND FINANCIAL PRESSURE ON PARENTS’ ATTITUDES

• The above results could be explained by the overall fatigue of parents of CWDs, lack of support and infrastructure, and the judgments that others exhibit towards families with CWDs. For example, a parent of a CWD mentioned that when she passes by people on the street, she hears them saying “this woman has a useless child”, other participants mentioned that those having CWD are often blamed for their child’s impairment. Family members of a CWDs are looked down upon and are sometimes treated as a non-marriage material who may also have “a gene of disability”.

“I am the one who knows the situation of my child and how valuable she is. Even though my husband abandoned me because of our CWD, I didn't abandon her” (FGD participant, a mother of a child with multiple disabilities)
THE EFFECTS OF SOCIAL NORMS, PEER AND FINANCIAL PRESSURE ON PARENTS’ ATTITUDES

- CWD are viewed negatively “due to the community that do not accept them as normal and do not facilitate them”. Most participants mentioned that families with CWD are stigmatized and discriminated against. Few reported that CWD are referred to as “disgusting and that their families do not eat with them at the same table”.

- Many referred to financial burden that CWD put on his/her parents, to include insufficient means to provide for and take care of CWD, inability to work full time, or work properly. One participant mentioned that when working on a farm, “a parent digs a small hole where the CWD will stay until the parent finishes his/ her work”.

- Many participants mentioned that parents hide their children at home, and do not take them anywhere. Some parents keep their children at homes “because they are afraid of what could have happened to them outside’ and others to prevent others from knowing about the existence of their child with disability.

- Some participants mentioned that while some families accepted having a child with disabilities, others believe that “spending time on them is wasting means because those children will not have any contribution to the family”.

- Having children with disabilities may also cause a conflict within a family, as was reported by many participants. Husbands and wives often blame each other for the child’s impairment and often men, as reported by some, abandon their families “as it's hard for them to provide care”.

42.8% of study (survey) participants agreed that most families in their community that have a child or children with disabilities try to hide them. Many FGD and KII participants, to include 52% of survey respondents reported that families with CWD are ashamed of them. One of the participants recalled a story of a fellow church member “who gave birth to a CWD and after that parents stopped coming to church, but I visited them, comforted them and after then, they come back at church”.

![Bar chart showing attitudes towards children with disabilities](chart.png)
Throughout the discussions it was observed, that children, were more accepting and understanding of CWD than adults. Children participants in FGDs vastly reported that regardless of the disability status, children are good (doing what is right) and many of them referred to both as hardworking (tending to participate in things) and together (being with other people). Many mentioned that there were all the same with some stating that “we all have blood, we breath the same air, born to parents”.
ATTITUDES TO CHILDREN WITH DISABILITIES BY CHILDREN WITH AND WITHOUT DISABILITIES

• When asked how children with and without disabilities similar, many responded that they were “all children, good and bad, hardworking and lazy”.

• When asked how children with and without disabilities differ, the most common responses were “he/she has a disability and I don’t” or "I have an impairment"; “they don’t go to school; do not do anything at home” or "I can't play like they can” and “I can’t go everywhere, like they can”, some children without disabilities stated that children with disabilities are “angry” and children with disabilities reported that they often face discrimination and are not welcomed by many. They also cannot socialize like children without disabilities.

• Few children with disabilities mentioned that they feel uncomfortable playing with children with certain disabilities, to include mental and intellectual disabilities. Some said that they can not share their clothes with the albino children, as they were afraid of getting infected. And many mentioned that they cannot share a secret with the children with mental disabilities.
Many children mentioned that children with disabilities are limited in what they can do because of their disability. The majority of children with and without disabilities reported that children with disabilities are said and lonely “due to their impairment” and because no one cares about them (see below charts for more details). Many CWDs mentioned that “CWDs are sad because they are not treated like others”, “..can't do all the things like those without disabilities do”, “..are sick”.

“All children are the same and their behavior depends on how they are being treated” (CWD FGD participant).
THE EFFECT OF EDUCATION AND KNOWLEDGE ABOUT DISABILITIES ON ATTITUDES TOWARDS CWD

Based on the study findings, there seems to be a correlation between the level of education and attitudes towards CWDs. Those participants with higher level of education and knowledge about disabilities tend to express more positive attitudes towards CWDs and are more understanding of their needs.
ATTITUDES TOWARDS CHILDREN WITH DISABILITIES BASED ON THEIR GENDER

• Majority of the study participants reported that boys and girls with disabilities get equal treatment (60.4%). According to most study participants, decisions around care for CWDs do not change based on the CWDs’ gender, they change based on the intensity of the disability.

• Many, however, mentioned that girls with disabilities require more attention. “A family of girl with disability brings more misery, as taking care of a girl is more expensive and depending on the age, girls might need more care than boys”. Girls become especially vulnerable, when they reach puberty.

• Few mentioned that girls with disabilities face more abuse and violence than the boys with disabilities.

“Having a child with disability is a problem for a family but having a girl with disability is even worse” (An adult FGD participant).
Many mentioned that social norms and attitudes towards CWD may differ depending on a type of a child’s disability and the intensity of his/her disability. For example, when asked if a CWD is treated differently from a child without disability many interview respondents reported that in general CWD requires a lot more attention and is more expensive to take care of. Speaking of the attitudes towards a particular type of a disability, study participants reported:

- **Physical disability:** Child with physical disability is considered by many as a problem. Some refer to them as “useless”, “they need a lot”, “they are difficult persons”. Many pity them and worry about the limits that their disability impose on them, including inability to play with others, and access school. Others mentioned that child with a physical disability is not treated any different from a child without disability.

- **Intellectual disability:** Many mentioned that children with intellectual disabilities are more likely to be “locked down”, “maltreated” or “abandoned”. The most common comments were “people fear them”, “see them as useless”, refer to them as “idiots”. “He is considered like a fool. For example, when he makes a mistake like any other child, the fault/ mistake is attributed to his condition”.

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**ATTITUDES TO CHILDREN BASED ON THE TYPES OF THEIR DISABILITY**

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- Mental disability: Some of the participants mentioned that most people “consider them (children with mental disabilities) as useless and do not take care of them”, others mentioned that this type of disability “is not understood by parents, there are no special schools for them, people don’t have knowledge about the care for such disability”. Other comments included: ”they are hidden”, they are on the streets”, “excluded”, and “there is no way to help them”.

- Sensory disability: Some mentioned that families tend to “overprotect” children with sensory impairments, prevent them from going to schools. Many reported that families adapt to their children’s disabilities, learn sign language and the ways to communicate with them. Others reported that children with sensory impairments are maltreated and not taken a proper care of. Many use demining names when referring to children with sensory disabilities.
In order to assess public attitudes and norms towards CWDs’ abandonment and education, study participants across FGDs, KIIIs, and survey were presented with vignettes about children with physical and intellectual disabilities. Participants were asked to reflect on where the best places for education and living for the fictional characters were, and whether people whose opinion was important to them approve or disapprove of their behavior/choice.
WHAT ARE THE SOCIAL, INCLUDING GENDER NORMS AROUND ABANDONMENT OF A CHILD WITH INTELLECTUAL DISABILITY?

- 79% of survey participants agreed that children with disabilities needed special institutions to live in. When presented with a story of 5-year-old Innocent, who was physically fit, but had troubles communicating, and did not seem to listen when spoken to, almost 82% of respondents reported that the best place for him to live in was an institution.

- The majority of survey respondents (75.4%) also believed that others in their communities would also recommend an institution for Innocent to live in and this opinion held on across the genders (75% of male and 76% of female population provided same responses). Only 10% of respondents believed that the place for Innocent to live in was with his family.
WHAT ARE THE SOCIAL, INCLUDING GENDER NORMS AROUND ABANDONMENT OF A CHILD WITH PHYSICAL DISABILITY

A story of a two-year old Gasore/Uwiduhaye, who could not “sit up, crawl, walk or stand without help of his parents or caregivers and needed to see a physical therapist regularly to help his movement” was presented to participants of FGDs and KII. Participants were asked about the better, according to them, place for him/her to live. Many responded that an institution would be a better place for him/her to live in, especially if his/her family was poor: “because it is expensive to care about them (CWDs)”, and “If the family has money - to stay at home is good, because they (CWDs) need affection from parents, need motherly love and need to be with his/her sisters and brothers”.

Many participants among those who spoke in favor of an institution, justified their opinions by the services that a specialized institution and its staff could offer to CWDs: “They can get more knowledge in life with his/her peers with same problems; It will increase his confidence than being in the family; it is expensive to care about them; he is not fully taken care of at home; Parents are busy looking for other children without disabilities, for what to feed the whole family with; They are limited in time and money”. Many spoke about the lack of appropriate infrastructure / transport.

Those few, speaking in favor of letting Gasore/Uwiduhaye staying at home, stated that parental care was important for a CWD: “children must live at home” and “the special care he/she needs, he/she can still get them while living at home”.

“Home is where she would be able to get parental love, but others wouldn't consider that because it is not their child” (FGD participant, parent of a child with disability).
WHAT ARE THE PREVAILING ATTITUDES OF RWANDANS TOWARD EDUCATING CHILDREN AND ADOLESCENTS WITH DISABILITIES?

• Many study participants said that children with disabilities are "mostly neglected and are not allowed to go to school while their siblings study”. The mentioned earlier perceptions and expectations of children with disabilities were repeated by study participants during the discussions of children’s abilities to participate in academic activities. Most of the survey respondents (63% of female and 67% male respondents) reported that CWDs lack social skills necessary for success in a general classroom, and 66% of female and 71% of male respondents believed that CWDs lack academic skills to participate in a general classroom.

• Although, 42% of survey respondents agreed that children with disabilities learn more rapidly in a general classroom rather than special classrooms, 64% of respondents across both genders responded that children with disabilities may create too much confusion in general classroom. They require a lot of attention, and their presence is detrimental for the children without disabilities (52.1%) with 21.8% reporting that the effect of the CWDs’ presence on his/her peers without disabilities will depend on the type of his/her disability.
Most of the participants (approximately 60% across survey and FGDs) reported that the best school for a child with intellectual and physical disabilities is a specialized school. Many reported that specialized school can “fully accommodate CWD and provide parents with enough time to work and care about other children”. Others also spoke about lack of training and low capacities of teachers in general schools to teach CWDs. “A CWDs should go to special school not to be frustrated by other student and by non trained teachers” and “Sometimes children without disabilities bully CWD” (FGD participants).
• Some respondents spoke in favor of general schools for CWDs. One of the participants of FGDs mentioned that child’s (speaking of a child with physical disability) “limitations won't prevent him from benefiting in a general school and that is where he will be able to learn how to integrate into the society with those without disabilities”. Almost 84% of survey participants agreed that CWD’s presence is beneficial for everyone, as it promotes the tolerance and acceptance of being different”.

• Many also believed that the majority in the community would choose an institution for the CWDs to live in: “a child like her still needs to be home and her special needs can be addressed while staying with parents, however others wouldn’t see it that way, because they believe a child with disabilities should be in an institution”. (FGD participant).

“That's (institution) the best place for her as many people can not be able to stand her (child with intellectual disability)” (Adult FGD participant)
Many study participants among children without disabilities reported that they have never seen children with disabilities, or only saw children with physical disabilities. Many reported that children with disabilities do not go to school, and they often see them at the markets begging. The discrepancies in the level of education was observed among the participants of the study as well, where children/participants without disabilities were overall more educated than children with disabilities (see the below table for more details).

"In my village, there are some CWDs who never leave their home, have never gone to church or elsewhere, enclosed home.” (FGD participant, a child without disability.)
HOW DO REFERENCE NETWORKS IMPACT PEOPLE’S BEHAVIOR TOWARDS CHILDREN AND ADOLESCENTS WITH DISABILITIES?

• When speaking about the people, whose opinion was important to them, most of the participants referred to husband/wife; family members; religious leader; neighbor; friend; community health worker; local political leaders; President of Rwanda; and NCPD coordinator.

• Many participants reported that their decision will not change based on the opinions of others. 51.3% of survey participants reported that the decision about the schooling and living situation for a CWDs does not at all depend on the opinion of other people in the community. FGD and KII’s participants echoed the sentiment with many stating that their decision will not change. “I only know and want what’s best for my child, thus I wouldn't comply with anyone”.

• Others reported that “the influence of others can play a great role” on their decisions and behaviors. Few stated that depending on the situation and explanations provided to them by their reference network, they can change their attitudes. “I will not comply with what others say. Don’t expect from me to satisfy them, but if I find that it (what they are saying) is helpful for my child, I can be flexible” (FGD participant).

“Some can accept his decision, others not, but what is important is what may help the child” (KII’s respondent)
THE IMPORTANCE OF THE REFERENCE NETWORK, ITS INFLUENCE AND THE CONSEQUENCES OF NON-COMPLIANCE

- Many study participants reported that it was important for them to listen to people’s opinion and do what they expect them to do in order to safeguard the relationship, to avoid conflicts and retain friendships and needed support. Many also mentioned that other people’s opinions “could be relevant” and could “open their mind” and it was important since “it is good to seek second opinion since one can’t know everything” (FGD participant).

- Some stated that non-compliance with a popular opinion will not cost them anything. Others stated that they will become a laughingstock ” if the result (consequence of their decision) is negative”.

- Many among parents of children with and without disabilities mentioned that they would “comply with others, if their ideas were an added value to the wellbeing and interest of the child”.
NUTRITION RELATED CHALLENGES THAT CHILDREN WITH DISABILITIES MAY FACE

• Most of the study participants reported that many parents do not have an adequate knowledge about healthy nutrition for either, child with and without disabilities. Parents are also too poor to provide balanced diet to their children.

• Few stated that parents do not care much about their children’s diet, especially when it comes to the children with disabilities.

• Some participants mentioned, that although parents acknowledge that children with disabilities may have special nutritional needs, they are unable to provide food to them because of the financial difficulties.

"It is not an easy question to respond, because not only parents of CWDs, but most parents have little knowledge on nutrition. Many parents of CWDs are poor and are not able to find healthy nutrition for their kids.” (KII’s respondent)
WHAT CAN BE DONE AND WHO CAN BRING THIS CHANGE

- When asked to reflect about the better life and future for CWDs, all participants spoke about the changes that need to be introduced on the societal and individual levels and that “society in general, local authorities, and every person is needed” to improve lives of CWDs.
  - Many spoke about the importance of new and appropriate infrastructure for CWD and increased access to assisting devices, appropriate health care and health insurance for CWD;
  - Many spoke about inclusive schools and their increased attendance by CWDs;
  - Reduced stigmatization and discrimination of CWDs and their families;
  - Respect of CWDs’ rights to education, health, participation in the community matters and activities;
  - Elimination of violence towards CWDs;
  - Increased Quality of Life of CWD, “I want to see children with disabilities and their families respected”, and “happy”; and
  - Increased knowledge and capacities of parents of CWD.
DISABILITY AWARENESS – AVAILABLE TOOLS FOR INFORMATION DELIVERY

• 46.9% of survey respondents reported that they’ve heard or have been informed about CWDs issues through different channels: 47% of respondents, reported to have heard information on children with disability on TV and Radio, 27% heard it from the community meetings. Some participants received information from social media, and few attended specialized trainings on the disability issues, and approximately 12% of the respondents have not heard any messages on children with disabilities.

• Speaking of the appropriate educational channels, many in addition to TV, radio, social media and community meetings suggested using face-to-face discussions, games, theatres/sketches, songs, and sport advertising to raise public awareness on children with disabilities.
THANK YOU

- “I want to see children with disabilities enjoying their rights as other children.” (FGD participant)