

***Knowledge, Attitudes and Practices (KAP) Case
Survey on Education of Children and Youth with
Disabilities in the
Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and
Nyarugenge
Republic of Rwanda***



Rwanda Education for All Coalition

1. *States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:*
 - (a) *The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;*
 - (b) *The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;*
 - (c) *Enabling persons with disabilities to participate effectively in a free society.*
2. *In realizing this right, States Parties shall ensure that:*
 - (a) *Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;*
 - (b) *Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;*
 - (c) *Reasonable accommodation of the individual's requirements is provided;*
 - (d) *Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;*
 - (e) *Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.*
3. *States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:*
 - (a) *Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;*
 - (b) *Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;*
 - (c) *Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.*
4. *In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.*
5. *States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.*

**ARTICLE 24 OF THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH
DISABILITIES (UNCRPD)**

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FOREWORD FROM REFAC

The Rwanda Education for All Coalition (REFAC) is pleased to present the “*Knowledge, Attitudes and Practices (KAP) Case Survey on Education of Children and Youth with Disabilities*”. This report is based on a survey designed to explore the current perceptions of the general public, people working in disability services, and education sector decision makers regarding education of children and youth with disabilities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge in Rwanda. The case survey in this report has highlighted significant gaps in the knowledge that the community and key stakeholders have about disability in the 5 Districts. Understanding these gaps will assist REFAC and other stakeholders in developing strategies to improve access to education services, both from the perspective of the service providers and from parents and families of children and youth with disabilities. This case survey also provides REFAC and other stakeholders with key insights into the attitudes of people in the target Districts in regard to education of children and youth with disabilities. With this information, the relevant education stakeholders and players in the target Districts will be better prepared to tackle misconceptions and develop positive attitudes towards children with disabilities.

The report provides a number of recommendations for changes in practice that will support education of children and youth with disabilities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge. REFAC is committed to improving the access to and quality of education services available for children and youth with disabilities and finds these recommendations to be a valuable guide. Based on the findings of this report, REFAC and stakeholders will design behavior change materials and through existing and newly designed communication channels, these materials will carefully guide all agents of change/champions for education of children/youth with disabilities in the districts of operations in making the improvements and changes recommended in the report in the most effective manner.

We wish to recognize the effort and input provided by a range of people and services to this KAP case survey. We have received informed and ongoing support from colleagues from the member organizations and this has been essential to the present work. Their diverse membership has enabled us to assimilate insights on education of children and youth with disabilities from different standpoints. The District Education Officers (DEOs) and Sector Education Officers (SEOs) from the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge have provided guidance regarding sampling and ethical procedure. We also value the role played by our member organizations operating in the targeted Districts, especially in the fieldwork component of this case survey. The latter has been accomplished in an efficient manner by a team of enumerators, to whom we also extend our thanks. The survey received guidance and reflections from an informal reference group, comprising a small number of nationally recognized practitioners and researchers in the field of children and youth with disabilities: we are grateful for their observations on our work as this case survey has progressed. Subsequent to the data analysis, a small group of practitioners in education of children and youth with disabilities responded to a request to provide suggestions for ground-level actions, based on the key areas of recommendation identified in the report: our gratitude is extended to them.

We cannot thank enough our esteemed partners, Education Out Loud (EOL) and OXFAM IBIS, for providing the resources to make this possible. Our gratitude also goes to all participants in the case survey for providing us with an insight into the knowledge, attitudes and practices of the community members in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge.

Finally, we would like to recognize the participation and engagement of all those in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge who contributed either as respondents to the case survey or as participants in the focus group discussions and informal interviews. The product of these activities informs the substance of this report; we therefore acknowledge these vital inputs, in the expectation that they have made a contribution to ensuring that education of children and youth with disabilities is maintained as a significant priority issue of focus in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge in the coming years.

Dr Safari Emmanuel
Chairperson, REFAC

EXECUTIVE SUMMARY

This KAP case survey recognized the internationally acknowledged definition for children with disabilities (CYWD). The term 'children with disabilities' in this case survey is used to refer to children up to the age of 18 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"*¹. However, the intention of this case survey was to secure participants' knowledge, attitudes and practices (KAP) based on their own understanding of the term.²

The survey was commissioned by REFAC in September 2020 as a *'Knowledge, Attitudes and Practices (KAP) Case Survey on Education of Children and Youth Disabilities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge'* as part of the implementation of the "Active Civil Society for Inclusive, Equitable and Quality Education in Rwanda" Project funded by the Education Out Loud through Oxfam Ibis. The intention of the survey has been to deliver a set of trustworthy data regarding the current extent, characteristics and provision (the knowledge, attitudes and practices) for education of children and youth with disabilities, together with a set of general recommendations for future action. The survey comprised five phases; the first phase scrutinized the existing literature on education of children and youth with disabilities in Rwanda; the second phase used three instruments to gather data from an agreed sample within the 5 Districts targeted in the project; the third phase comprised an interrogation of the data generated; the fourth phase provided a full draft of the final report for scrutiny by REFAC and Stakeholders; and the fifth and last phase constituted the delivery of a workshop, supported by appropriate resources, regarding the survey findings.

The survey has generated data that provide evidence on the KAP of education of children and youth with disabilities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge, primarily from the perspectives of families with children and youth with disabilities and those without. Key findings thus relate to both groups. In addition, data were secured from education policy implementers, education service providers and religious leaders. Data were secured using both quantitative and qualitative instruments: a household survey questionnaire, a focus group discussion tool and informal interviews with key individuals working in the field. Data reporting and analysis have been undertaken in recognition of the accepted view that 'Knowledge', 'Attitudes' and 'Practices' are interrelated, in that respondents who have a greater Knowledge regarding education of children and youth with disabilities will express Attitudes of concern regarding issues relating to education of children and youth with disabilities and incorporate them within their Practice.

Survey findings

The survey revealed that knowledge regarding education of children and youth with disabilities was extremely limited. This applied to both legislation and provision of relevant services for this group of children. The term 'disability' was generally defined by respondents in narrow terms as representing mainly those individuals who have severe physical or sensory impairments, with a consequent tendency to marginalize those who experienced other forms of disability. This has implications for service delivery. Attitudes towards children and youth with disabilities and their families were more positive among younger respondents and more highly educated respondents. The absence of knowledge related to children and youth with disabilities is a significant factor in the responses of the general population, who did not perceive intellectual impairment as a disability. Families of children and youth with disabilities felt that the support that they received both in school and within their community was inadequate. They stated that most of the support came from within their wider family circle and that they felt isolated from other families living with disability.

Among the general population there was a consensus that educational and social provision for children and youth with disabilities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge was improving, and that the support provided by the state was adequate. This is in contrast to families with children and youth with disabilities, who were less positive and felt that they received less support than they

¹ *United Nations Convention on the Rights of Persons with Disabilities, Article 1.*

² *There is, however, a recognition that the terms 'disability', 'special educational needs' and 'learning difficulties' are frequently used interchangeably, both in the literature and by participants in this survey.*

required. The data collected indicate that there are a range of enabling factors that provides a platform for potential future developments in support of education of children and youth with disabilities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge . It is important to recognize that these are at least inferentially associated with the overall national approach to supporting education and social welfare for all children in the country and linked to developments in provision during the last decade or more.

Engagement with schools and teachers during the research process, although not extensive, did suggest that there is some willingness to address issues of educational and social exclusion. There was also some evidence of an awareness of the need to provide disability related professional development for key personnel working with children and youth with disabilities. However, such positive indicators are counterbalanced by omnipresent barriers, which co-incidentally are reflected in many other national settings worldwide.

These findings infer synergies between knowledge levels of children and youth with disabilities and resulting positive or negative attitudes towards these children. The connection to formal practices is less obviously demonstrated, given that the case survey did not constitute a prevalence survey. Parental practice, however, was informed by acquired, experiential knowledge of their children with disabilities.

Recommendations and challenges

Following data analysis, four target areas have been identified from which recommendations regarding policy, provision and practice for children and youth with disabilities are made. These relate to systems challenges and change, families of children and youth with disabilities, the general population and education professional groups.

The report acknowledges several challenges – both methodological and procedural – that the survey team encountered. Whilst these do not prejudice the validity or reliability of the findings, they raise potential issues for development, especially in the application and use of qualitative evidence. In addition, the existing data set offers opportunities for future disaggregation, particularly between knowledge and attitudes.

1.1. CONTEXT AND INTRODUCTION

1.1 Context

Kamonyi District is located in the Southern Province, with 12 Sectors, 59 Cells and 317 Villages, with a population of 340,501, covering an area of 655.5 km², bordering five Districts of Muhanga, Ruhango, Nyarugenge, Gakenke and Bugesera. According to the District officials, Kamonyi District aspires to the fact that education is the foundation of people's well-being because it is the foundation of basic knowledge and basic learning which helps the human mind to think and thrive. According to the District officials, education begins in the family and continues in front of the teacher at schools where the child is trained in basic skills that will help him or her make a living based on his or her abilities. In Kamonyi District, education has been developed through schools of all levels and there are about 102 nursery schools, primary and secondary schools in the district.

Bugesera District is one of the Eastern Province's districts, located in the southeastern part of the country. Based on the 2012 Census, Bugesera District has a population of 361,914. Bugesera district is a thriving area as it is not far from the urban areas, which are within 15 kilometers of Kigali City. The District Education Unit in Bugesera is represented by 4 staff including the Head of Unit, a staff member in charge of secondary schools and TVET, the staff in charge of primary schools, nursery schools; a staff responsible for adult literacy and numeracy as well as a school construction supervisor. There are 120 schools in Bugesera Districts, including church subsidized schools, public and private schools.

Kicukiro District is one of the 3 Districts which constitute the City of Kigali. Situated in the south-east city of Kigali, the District is made up of ten (10) administrative sectors, 41 cells and 333 administrative villages; covering a total area of 166.7 km². According to the 2012 Population Housing Census, the total population of Kicukiro District is 319 661; with male population being 162 755 (50.9%) and female population 156 906 (49.1%). The majority of the population of Kicukiro District is young, with 87% of the population aged less than 40 years old, and 46% less than 19 years old.

Nyarugenge District is one of the 3 Districts of Kigali City, with 10 Sectors, 47 Cells and 350 Villages. This District has an area of 134 km² with a population of 284,561 of which 136,429 (47.9%) are women and 148,132 (52.1%) are men, with the density of 2,125 inhabitants/km². About 86 % of its surface is rural and little populated. The district has 40 pre-primary schools, 42 primary schools, 34 secondary schools with students amounting to 2,125 males and 2,062 females in pre- primary, 25,899 males and 25,210 females in primary school and 7,458 males and 7,247 in secondary school. The mean walking distance to a primary school is 28.6 minutes in rural areas, while it is 27.2 minutes at the national level. Even if there is a need to increase the number of nursery classrooms, Nyarugenge District enjoys an average of almost four classrooms per school which is a good figure compared to most of the other districts, where most of the schools have one classroom.

Gasabo District is another one of the 3 Districts of Kigali City, with 15 sectors and covering an area of 430.30 km². This District has a total population of 530,907, with a density of 1,237/Km². The district has built 524 primary and secondary classrooms for the 9-year and 12-year basic education programs and 85 classrooms for nursery schools among other education infrastructures.

Like in any other Districts of the country, the 5 districts described above follow and aspire to the education targets and indicators as set by the Ministry of Education (MoE), in its Education Sector Strategic Plan of 2018/19-2023/24. This Strategic Plan recognizes that disabilities are still a major factor affecting children's access to school in Rwanda. Affirming that, children with disabilities, in 2016 out of a total of 185,666 children enrolled in pre-primary education, just 1,545 children were identified as having a disability (MINEDUC, 2016b). In primary schools, however, data reveal those with disabilities to be 0.75% of the total number of children enrolled, a percentage which has not changed significantly over the last three years. This represents fewer than 1% of the enrolled students, falling far short of the expected numbers represented within the population. The numbers of students with a disability form just 1% of the total enrolled in secondary education in 2016 (MINEDUC, 2016b). Students with disabilities are under-represented, with just 432, or 0.48%, of all students enrolled in tertiary education having some form of disability. It farther asserts that ensuring that all schools in Rwanda are child-friendly and disability-friendly is still a challenge

and education for children with disabilities also demands strong coordination between different Ministries and agencies beyond the education sector, particularly those in the Health, Social Protection and Local Governance sectors, which itself contains the challenge of coordination across multiple sectors and Ministries. These national challenges are equally noted in respect of children with 'special needs' in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge where the Government's initiatives to enhance educational access for children with special needs remains a persisting challenge owing to the limited number of special schools, facilities, support services and capacity of the teachers. The most recent statistics show that the number of secondary students with disabilities keep decreasing every year. For instance, The number of secondary school learners with disabilities decreased from 4,557 (2,253 male and 2,304 female) in the school year 2017/18 to 4,202 (2,194 male and 2,008 female) in the following school year 2018/19.³ Similarly, the number of learners with disabilities enrolled in TVET schools decreased from 560 in 2017 to 483 in 2018, with male learners more present in the schools (53%) than their female counterpart (47%).⁴ Additionally, available evidence shows that many children and young boys and girls with disabilities are not attending school and a number of drivers are contributing to their low enrolment from nursery to the tertiary education; from systemic barriers requiring systemic changes to the situational challenges such as the social and cultural norms which require general behavior change or change in attitudes towards education of children and youth with disabilities.

1.2 Introduction

It is against the contextual background presented above that the present case survey has been configured. It was commissioned by REFAC in September 2020 as a '*Knowledge, Attitudes and Practices (KAP) Case Survey on Education of Children and Youth Disabilities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge*' as part of the implementation of the "Active Civil Society for Inclusive, Equitable and Quality Education in Rwanda" Project funded by the Education Out Loud through Oxfam Ibis. The scope of the survey was threefold:

1. Provide an overview of the current position regarding knowledge, attitudes and practices of a range of stakeholders towards disabilities and disability services, with an emphasis on education of children and in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge;
2. Identify both achievements and barriers in provision and to identify priorities for future development to inform a fit-for-purpose behavior change communication activities;
3. Make recommendations to key stakeholder groups working with children and youth with disabilities and their families to promote the effective delivery of education services.

The intention of the case survey has been to deliver a set of trustworthy data and attendant recommendations regarding the current extent, characteristics and provision (the knowledge, attitudes and practices) for children and youth with disabilities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge. In addition, it would contribute to the formulation of a behavior change communication strategy for the education of children and youth with disabilities. The work undertaken comprised five interlinked phases, each with a designated output. The survey adopted a collaborative approach in all its phases and was underpinned by the project leadership and management.

The first phase scrutinized the existing literature on education of children and youth with disabilities (both recognized academic sources as well as the so-called 'grey' literature) and resulted in a detailed review of the current situation in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge. It also defined and tested a set of three instruments that were subsequently used to generate data. In addition, an appropriate set of ethical protocols was established and ratified, and fieldworkers were identified and trained. The second phase used the three instruments to gather data from an agreed sample; thus, a household survey, focus group discussions and a set of interviews with nominated key informants were operationalized. Data were to be collated and placed in a secure electronic repository.

The third phase comprised an interrogation of the data generated and preparation of illustrative data materials for subsequent use in the reporting stage of the project. The fourth phase provided a full draft of the final report for scrutiny by REFAC and stakeholders. It also comprised a set of recommendations, based on data evidence, to highlight ways forward in meeting the education needs of children and youth with

³ Rwanda Ministry of Education (2018) Education Statistics

⁴ *idem*

disabilities; a user-friendly research summary was also constructed to assist in a dissemination effort. The fifth and last phase resulted in the delivery of a workshop, supported by appropriate resources, regarding the project's findings alongside the presentation of a framework for a behavior change communication plan of activities for the education of children and youth with disabilities. These events principally involved key stakeholders from the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge.

2. METHODOLOGY

2.1 Survey orientation

A mixed-methods approach, using data collection tools to generate both quantitative and qualitative data, was adopted to ensure that multiple perspectives regarding education of children and youth with disabilities were gathered. These methods and instruments were considered to be complementary rather than hierarchical. Some triangulation of data was included, which provided an additional lens through which to view knowledge, attitudes and practices. Limitations regarding the low sample of children and youth with disabilities and the volume and efficacy of narratives from the interviews and focus groups require that the findings may need to be interpreted with care.

The quantitative data collection tool was designed to elicit information concerning knowledge, attitudes and practices towards children and youth with disabilities from a sample of the population in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge. A sample of 150 households was surveyed from ten sectors (2 sectors per district) to capture data. About 60% of the participating households lived in urban and 40% in rural households, reflecting the overall national urban/rural ratio. 60% of the participating households involved female respondents as opposed to 40% of male counterparts. The household survey questionnaire was undertaken prior to setting up a series of focus group discussions and interviews, involving key participants and stakeholders who had direct involvement in the education, social care and welfare of children and youth with disabilities. In addition, 20 stakeholders (2 teachers and 2 CSOs per district), 5 District Educations Officers and 10 Sector Education Officers participated in the survey as Key Informants Interviewees. The survey further involved 120 learners with disabilities among whom 75% were female and 25% were male participants. Overall, the survey involved 305 participants, with more than 65% being female participants.

2.2 Survey Tools

Data were first collected via the 5-page survey questionnaire (see Appendix 1). Trained enumerators visited households in ten sectors and completed the survey tool with the respondent using an electronic tablet. The questionnaire used both closed and open questions to gather data. The initial section of the tool gathered information to identify the location of the respondent and other demographic information. It was intended that data would be collected regarding the composition of respondents' households; however, the enumerators in the field collected data regarding only the respondent and one other person in each household. This was identified only at the data analysis stage. Where families included a child with disabilities, demographic data were collected regarding these children and the impact of their impairments.

All respondents were asked questions on their knowledge, attitudes and practices regarding children and youth with disabilities. A Likert scale was used to gather attitudinal data via 21 questions across five domains: society and support, personal attitude towards disability, contribution of CYWD to society, education and inclusion, and protection. A stratified multistage cluster sampling design was utilized (see Appendix 2), which has been regarded as appropriate within KAP studies. In addition, narrative data were generated using focus groups (see Appendix 3). These were established to enable interested key stakeholders to discuss their experiences and present viewpoints regarding provision made for children and youth with disabilities in the 5 Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge. There were 10 focus group discussions, distributed across both urban and rural districts of the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge. Data from these groups were analyzed using an accepted method to identify a set of key themes, which could subsequently be triangulated with other data sets. Finally, informal interviews were conducted with several key informants who were purposively identified, working directly with children and youth disabilities within the districts/sectors.

Data collection, reporting and analysis were undertaken in recognition of the accepted view that 'Knowledge', 'Attitudes' and 'Practices' are interrelated, in that respondents who have a greater Knowledge regarding CYWD will express Attitudes of concern regarding issues relating to CYWD and incorporate them within their Practice. Such relationships might be negative, in that there may be considerable gaps between what is said (informed by Knowledge and Attitudes) and what is done (Practice). 5 local locally employed enumerators were used to collect data, using the instruments described; this group was trained by an experienced training consultant, with inputs from the REFAC Coordinator.

2.3 Pilot survey

Following extensive preparation and training, a pilot of the questionnaire was conducted on Day 4 of the enumerator training programme. Locally employed enumerators conducted the pilot; supported by a supervisor designated by the lead consultant. During the pilot, enumerators were accompanied by observers from REFAC. The pilot was conducted in two locations selected by REFAC, the Districts of Kamonyi (representative of rural districts) and Gasabo (representative of urban Districts). The local enumerators used tablets to collect data. In both locations, the pilot began with enumerators conducting listings of households to secure a verified sample. Enumerators reported their findings to their supervisors and proceeded to gather data from households in the identified sample.

Following the pilot data collection, the local enumerators and supervisors fed back on the process in the field on both content and process. Overall, feedback from enumerators and observations by the consultant and REFAC team indicated that the training had been appropriate and that the questionnaire had been fit for purpose. As a result of the pilot, some challenges were identified and these were addressed within the subsequent training, ahead of the main fieldwork. They included:

- a. lack of families with children and youth with disabilities in selected households during pilot;
- b. absent heads of household at times when enumerators called;
- c. quality of initial introductions;
- d. difficulty with gathering data for the Likert scale; and
- e. enumerators' health and safety because of COVID-19;

These challenges were resolved as follows:

- a. *Lack of families with CYWD in selected households during pilot:* As the general population was to be sampled in the full survey and a robust rubric was applied to sampling, it was agreed that the full sample of households would be representative, so this issue was unlikely to prevail.
- b. *Absent heads of household at times when enumerators called:* During the pilot, particularly in the urban area, heads of households and indeed members of households were sometimes not at home when the enumerators called. The enumerators indicated the importance of knowing what times they should call at households, particularly outside work hours when heads of households were likely to be in. It was acknowledged that their knowledge of local areas would be important in this regard.
- c. *Quality of initial introductions:* Enumerators identified that their initial introductions to householders could sometimes be awkward and this could cause difficulty in gaining the confidence of a respondent. The pilot indicated the value of all enumerators using one model of wording for their initial introductions as well as the need for enumerators to be able to identify themselves as undertaking work on behalf of the consultant and REFAC. Enumerators were given a card to take into the field that featured the wording for their introduction. REFAC and the consultant agreed to liaise to ensure the enumerators had name badges that showed the organizations with which the consultant was working for the KAP survey.
- d. *Difficulty with gathering data for the Likert scale:* Enumerators indicated that repetition of the Likert scale caused difficulties in data collection. Following the pilot, all enumerators were issued with a visual resource for the Likert scale on the back of their introduction card.
- e. *Enumerators' health and safety amidst COVID-10:* As employees of the local consultant, enumerators' safety and health were the responsibility of that organization. Nevertheless, following the pilot, protocols for enumerators' safety and health amidst COVID-19 were highlighted for discussion in a training session.

2.4 Ethical consideration of the case survey

A set of clearly identified principles informed the way in which the survey team operated both in the field and in its approach to data management and reporting. These principles in turn provided the basis of the ethical management of the research activities and their supporting actions, including the reporting of outcomes. All team members were required to comply with a number of statutory protocols, including REFAC's safeguarding policies, code of conduct and anti-corruption policies. In addition, the survey's methodology and instruments were scrutinized by REFAC's Board of Directors which provided helpful inputs in refining the tools and gave approval for their use in the survey.

All team members in the survey have participated in fieldwork directly involving vulnerable children and young people, including children and youth with disabilities. In undertaking this work all participating staff were required to regularly assess their level of compliance with the agreed principles and statutory protocols.

3. CASE SURVEY FINDINGS: QUANTITATIVE DATA

3.1. Orientation

This section presents the results of the household survey questionnaire undertaken across the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge in September 2020. Demographic information on the sample is presented before moving on to discuss information obtained on the knowledge, attitudes and practices regarding both the sample as a whole (n=305) and drawing comparisons between those respondents whose families included children and youth with disabilities (n=120) and those whose did not (n=150). Further analyses were undertaken to compare the attitudes of respondents by gender, age and education.

Quantitative data were collected in accordance with the methodology agreed with and approved by REFAC Coordination. The locally employed enumerators were trained to administer the questionnaire tool prior to data collection in the field, which included a pilot survey, designed to validate the instrument developed. Following this training, the fieldwork was undertaken throughout the months of September 2020. Data collected were sent to the REFAC Coordination in early September 2020. Data cleansing was undertaken, resulting in a final data set comprising 305 responses. Data analysis was undertaken in early September 2020. All percentages presented in this section are rounded to one (nearest) decimal place. Selected key data are presented graphically.

3.2. Demographic information about the sample

The sample included in the survey were selected by the locally employed enumerators from a total of 915 respondents within the identified sectors (183 equally distributed per District) and a total of 305 respondents was surveyed by the enumeration team. Respondents came from 10 sectors in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge (2 sectors per District). Just 60% of respondents (n=183, 60 per cent) lived in urban households, while just 40% (n=122, 40 per cent) lived in rural households, reflecting the overall national urban/rural ratio. The geographical location of respondents by sectors (and identifying the sectors surveyed within each District) is shown in the Table 1 below.

Survey Participants per District/Gender	Nyarugenge		Kicukiro		Gasabo		Kamonyi		Bugesera		Total		All
	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	
District Education Officer (DEO)	1	0	1	0	1	0	1	0	1	0	5	0	5
Sector Education Officer (SEO)	1	1	1	1	1	1	1	1	1	1	5	5	10
Education Stakeholders (2 Teachers, 2 CSOs)	2	2	2	2	2	2	2	2	2	2	10	10	20
Parents/caregivers (60% female & 40% male)	18	12	18	12	18	12	18	12	18	12	90	60	150
Learners with disabilities (75% female and 25% male)	18	6	18	6	18	6	18	6	18	6	90	30	120
	61		61		61		61		61		305		
In total, 15 education stakeholders, 5 national CSOs and 285 education community members (5 District Education Officers and 10 Sector Education Officers, 150 parents/caregivers, 120 learners with disabilities) participated in the KAP survey											200	105	305
Urban respondents	60%											183	
Rural respondents	40%												122
Female respondents	66%												
Male respondents	34%												

3.2.1 Respondents (Age, Gender and Disability)

Responses were sought from both adults and children/youth and of the total 305 participants, 185 (61 per cent) identified themselves as adults (aged 25 and above years old) while 120 (39 per cent) were identified as children and youth (aged below the age of 25). As seen in the table, in total, 105 participants (34 per cent) were male and 200 (66 per cent) were female.

Survey Participants per District/Gender	Nyarugenge		Kicukiro		Gasabo		Kamonyi		Bugesera		Total		All
	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	
District Education Officer (DEO)	1	0	1	0	1	0	1	0	1	0	5	0	5
Sector Education Officer (SEO)	1	1	1	1	1	1	1	1	1	1	5	5	10
Education Stakeholders (2 Teachers, 2 CSOs)	2	2	2	2	2	2	2	2	2	2	10	10	20
Parents/caregivers (60% female & 40% male)	18	12	18	12	18	12	18	12	18	12	90	60	150
Learners with disabilities (75% female and 25% male)	18	6	18	6	18	6	18	6	18	6	90	30	120
	61		61		61		61		61		305		
<i>In total, 15 education stakeholders, 5 national CSOs and 285 education community members (5 District Education Officers and 10 Sector Education Officers, 150 parents/caregivers, 120 learners with disabilities) participated in the KAP survey.</i>											200	105	305
	183											122	
Urban respondents	60%												
Rural respondents	40%												
Female respondents	66%												
Male respondents	34%												

From the children and youth group, children (aged below the age of 18) constituted 75 per cent (90 participants of out 120) while older youth constituted 25 per cent of the sampled children and youth group (30 participants out of 120). (See details in Table 2 below)

Table 2: Age distribution per age brackets

Survey Participants per District/Age Group	Nyarugenge		Kicukiro		Gasabo		Kamonyi		Bugesera		Total		All	
	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male		
District Education Officer (DEO)	1	0	1	0	1	0	1	0	1	0	5	0	5	
Sector Education Officer (SEO)	1	1	1	1	1	1	1	1	1	1	5	5	10	
Education Stakeholders (2 Teachers, 2 CSOs)	2	2	2	2	2	2	2	2	2	2	10	10	20	
Parents/caregivers (60% female & 40% male)	18	12	18	12	18	12	18	12	18	12	90	60	150	
Learners with disabilities (75% female and 25% male)	18	6	18	6	18	6	18	6	18	6	90	30	120	
Adult (over 25 yo)	37		37		37		37		37		185			
Children and youth	24		24		24		24		24		120			
<i>In total, 15 education stakeholders, 5 national CSOs and 285 education community members (5 District Education Officers and 10 Sector Education Officers, 150 parents/caregivers, 120 learners with disabilities) participated in the KAP survey.</i>											305			
Adult respondents	61%		Children and youth respondents						39%					
			Children	90	75%	Youth	30	25%						

Over half of respondents were aged between 30 and 49 years (59 per cent); there were also large numbers aged 20–29 years (30 per cent) and 50–59 years (11 per cent) (see Table below).

Survey Participants per District/Age Brackets	Nyarugenge		Kicukiro		Gasabo		Kamonyi		Bugesera		Total		All
	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	
District Education Officer (DEO)	1	0	1	0	1	0	1	0	1	0	5	0	5
Sector Education Officer (SEO)	1	1	1	1	1	1	1	1	1	1	5	5	10
Education Stakeholders (2 Teachers, 2 CSOs)	2	2	2	2	2	2	2	2	2	2	10	10	20
Parents/caregivers (60% female & 40% male)	18	12	18	12	18	12	18	12	18	12	90	60	150
Learners with disabilities (75% female and 25% male)	18	6	18	6	18	6	18	6	18	6	90	30	120
Adult (over 25 yo)	37		37		37		37		37		185		
Aged between 20 and 29 yo	11		13		11		11		11		56		30%
Aged between 30 and 49 yo	22		22		22		22		22		110		59%
Aged between 50-59	4		2		4		4		4		20		11%
Children and youth	24		24		24		24		24		120		
Aged below 18	17		17		17		17		17		85		71%
Aged between 18 and 24 yo	7		7		7		7		7		35		29%

3.2.2. Respondents' Educational Status

The mean length of time in education of respondents was four years. Over 30 per cent were identified as having received no formal education (n=106, 35 per cent) (see table below). Overall, 66 per cent of female respondents had received no formal education. Only 19 respondents (6 per cent of the sample) held a bachelor's or postgraduate degree, 66 per cent of whom were women.

Survey Participants per Years in Education	Nyarugenge	Kicukiro	Gasabo	Kamonyi	Bugesera	Total	%	Female	Male
No formal education	15	17	15	32	27	106	35%	70	36
1-3 years	20	11	15	13	15	74	24%	49	25
4-6 years	12	17	15	11	13	68	22%	45	23
7-9 years	6	8	8	1	2	25	8%	17	9
10-12 years	4	3	4	1	1	13	4%	9	4
13-15 years	4	5	4	3	3	19	6%	13	6
16-20 years	0	0	0	0	0	0	0%	0	0
Over 20 years	0	0	0	0	0	0	0%	0	0
	61	61	61	61	61	305		201	104

3.2.3. Composition of respondents' households

Unfortunately, we cannot present in-depth information regarding the composition of respondents' households as data were collected only on the respondent and one other person in each household. This arose as a problem post-piloting and was identified as an issue only at the data analysis stage. As a result, we only can state that 290 respondents (95 per cent) lived in multi-person households and that 15 respondents (5 per cent) lived alone.

3.2.4. Families within the sample that include CYWD

Seventeen families (3 per cent of the sample) identified that they had a child with a disability: eight with a boy and nine with a girl. Eleven lived in rural areas (Kamonyi District =6 and Bugesera District=5). Six respondents lived in urban districts (Nyarugenge District=2, Kicukiro District=1 and Gasabo District=3).

(a) Range of disabilities

One of these families provided very limited information about their daughter. The age range of child with disability is 2 years to 17 years. Over half of these children had difficulties in multiple areas of functioning.

- (i) Difficulty seeing even if wearing glasses (N=2)
- (ii) Difficulty hearing even if using hearing aid (N=6)
- (iii) Difficulty walking or climbing stairs (N=3)
- (iv) Difficulty remembering or concentrating (N=4)
- (v) Difficulty with self-care (N=5)
- (vi) Difficulty communicating (N=11)
- (vii) Difficulties in multiple areas (2 or more) (N=10)

(b) Education and care

Forty-one per cent of these children (n=7) attended their local school; the same number (n=7) were not in education, and their mother (n=5) or grandmother (n=1) stayed at home to look after them during the day.

(c) Play and socialization

With regard to the 17 children/youth with disabilities, 14 of them (82.4 per cent) played with other children/youth within their family. Thirteen (76.5 per cent) played with other children outside the family: 11 visited their friends' homes to play, while two played with their friends only at school.

(d) Future aspirations

With regard to what parents thought their children would be doing at the age of 18, the majority thought their children would still be at home, either working, surveying or not working.

(e) Support for families living with disability

All 17 respondents with a child with disabilities identified their family as being their main source of support. Other sources of support identified were specialist medical (n=5), general medical (n=2), school (n=1) and neighbors (n=1). Three respondents felt that support had always been adequate, while 14 respondents felt that the levels of support received had been insufficient. Only 4 of the 17 respondents (23.5 per cent) knew of another family that had a child with disabilities.

3.3. Children and youth with disabilities – Knowledge

3.3.1. Understanding with regard to what disability is

Respondents were asked to identify whether they agreed or disagreed with a number of statements regarding what comprised a disability. Data are first presented with regard to the whole data set (n=305). The responses of families that include CYWD (n=17) are then compared with those that do not.

(a) All respondents

A very high majority of respondents (>90 per cent) felt that individuals who had a total loss of vision, a total loss of hearing, or those who needed to use a wheelchair would be considered as having a disability. Slightly fewer felt that those who had conditions limiting the use of their hands or those who needed a walking aid had a disability. Fewer than two thirds of respondents considered individuals who used hearing aids as having a disability; and only just above half of the respondents considered those needing glasses or those with learning difficulties as having a disability.

- (i) A person/child who has a total loss of vision has a disability 94.6% (N=289)
- (ii) A person/child who has low vision and requires glasses has a disability 50.4% (N=154)
- (iii) A person/child who has a total loss of hearing has a disability 93.4% (N=285)
- (iv) A person/child who has poor hearing and requires hearing aids has a disability 64.2% (N=196)
- (v) A person/child who needs to use a wheelchair has a disability 93.9% (N=286)
- (vi) A person/child who needs to use a walking aid (such as a stick) has a disability 77.7% (N=237)
- (vii) A person/child who has a condition that limits the use of their hands has a disability 87.0% (N=265)
- (viii) A person/child who has difficulties with learning at the same pace as others has a disability 51.7% (N=158)

(b) Comparison of attitudes of families with CYWD and those without

With regard to families with CYWD, attitudes regarding what comprised a disability were generally similar to those of the whole sample. The only point of divergence was with regard to learning difficulties, where just over 70 per cent of this group considered this a disability, compared with 51.7 per cent across the whole sample. The differences between the responses of those families living with disability (n=17) and those that were not (n=288) were subjected to chi-square analysis. None of the differences between the two subsets' responses to these statements are statistically significant.

3.3.2 Awareness of national legislation regarding children and youth with disabilities

(a) **All respondents:** Respondents were asked if they were aware of any national legislation regarding children and youth with disabilities. In response, 50 (16.3 per cent) said that they were, but few were able to give specific examples when asked what legislation they were aware of (two respondents referred to 'Special Needs and Inclusive Education', one respondent referred to National Council of Persons with Disabilities). Other respondents referred to the existence of, for example, special schools or disability organization, or made statements such as "there should be legislation since all are getting opportunities to education", or "they have a same opportunity as other children".

(b) **Families with children and youth with disabilities:** Four of the 72 respondents who were parents of CYWD (23.5 per cent) said that they were aware of national legislation regarding such children and youth, but none could specifically name any legislation.

3.3.3. Awareness of education services for children and youth with disabilities

(a) **All respondents:** A total of 58 respondents (19 per cent) said that they were aware of local services for children and youth with disabilities within their communities. A number of respondents identified Early Childhood Care and Development (ECCD) programmes or specific schools in their areas. Some spoke of providing charity or food to families in their areas, and of governmental financial support. Others mentioned the provision of medical aids. With regard to services at a national level, 108 respondents (35.3 per cent) said that they were aware of services. Respondents spoke of the provision of aids, health provision, educational provision, financial support, etc.

- (b) **Families with CYWD:** Only two of the parents of CYWD (12 per cent of the total parents/caregivers) said they were aware of any services for CYWD in their areas – ECCD and hospital services. Twelve families (71 per cent) were aware of national services.

3.3.4. Awareness of health services

- (a) **All respondents:** In total, 159 respondents (52 per cent) stated that they were aware of health services that assist children and youth with disabilities and their families. Specific reference was made to the “centre de santé” in their neighborhood, district hospitals, medical treatment (such as check-ups and operations) at health facilities, hospital transport, home visits and the provision of aids and medication.
- (b) **Families with CYWD:** Nine of these families (52.9 per cent) said they were aware of health services – again, reference was made to “centre de santé”, hospitals and the provision of medication.

3.3.5. Awareness of education services

- (a) **All respondents:** With regard to education services that assist children and youth with disabilities and their families, 201 respondents (65.9 per cent) identified that they were aware of such services. The most well-known services were the centers caring for children and youth with disabilities across the county. (*See table below*)

Institution	Parents	Staff	Children
Amizero y'Ubuzima	7	8	10
APAX Murrumba	0	3	4
ASFA Muganza	No figure	No figure	0
AVEH Umurerwa	5	5	0
Centre Amizero	0	3	11
Centre de Jeunes Sourds Muets de Saint Gabriel - Huye	0	2	0
Centre Mugombwa	4	2	10
Centre Nyanga	0	5	0
Centre Orthopédique et Chirurgie de Rilima	3	7	8
Centre Ryoha	9	0	8
Centre St François	0	5	No figure
Centre Urugwiro	8	5	7
HRD Muhanga	0	5	6
HVP Gatagara Humura	4	12	0
HVP Gatagara Huye	0	3	No figure
HVP Gatagara Nyanza	12	6	9
HVP Gatagara Ruhango	7	3	8
Inshuti Zacu	5	5	0
Institut Filippo Smaldone	0	3	8
Izere Mubyeyi	17	4	0
Komera Centre	8	No figure	4
Ngwino Nawe	6	5	5
Nyabihu School for the Deaf	7	5	8
RBC Ineza Kabaya	9	3	0
St Francois d'Assise Ruhango	7	2	4
Ubumwe Community Centre	1	3	3
Vision Jeunesse Nouvelle	4	0	5
Wibabara	15	2	4
Youth Friendly Centre Rubavu	0	2	4

- (b) **Families with CYWD:** Twelve families (70.6 per cent) were aware of national services. Again, reference was made to the centres caring for children and youth with disabilities mentioned in the table above.

3.4. Children and youth with disabilities – Attitudes

Respondents were asked their opinions in respect of 21 statements regarding children and adults with disabilities, across five domains: (i) Society and support, (ii) Personal attitude towards disability, (iii) Contribution, (iv) Education and inclusion; and (v) Protection. A seven-point Likert scale was used to gauge opinion. The categories offered to respondents were as follows: *Strongly Agree*, *Agree*, *Slightly Agree*, *Neither Agree nor Disagree*, *Slightly Disagree*, *Disagree*, *Strongly Disagree*. An eighth category (*Don't know*) was also provided for use if respondents felt they had insufficient knowledge to give an opinion. The data were merged into four simplified categories: *Agree* (all degrees of agreement added together); *Neither Agree nor Disagree*; *Disagree* (all degrees of disagreement added together); and *Don't Know*.

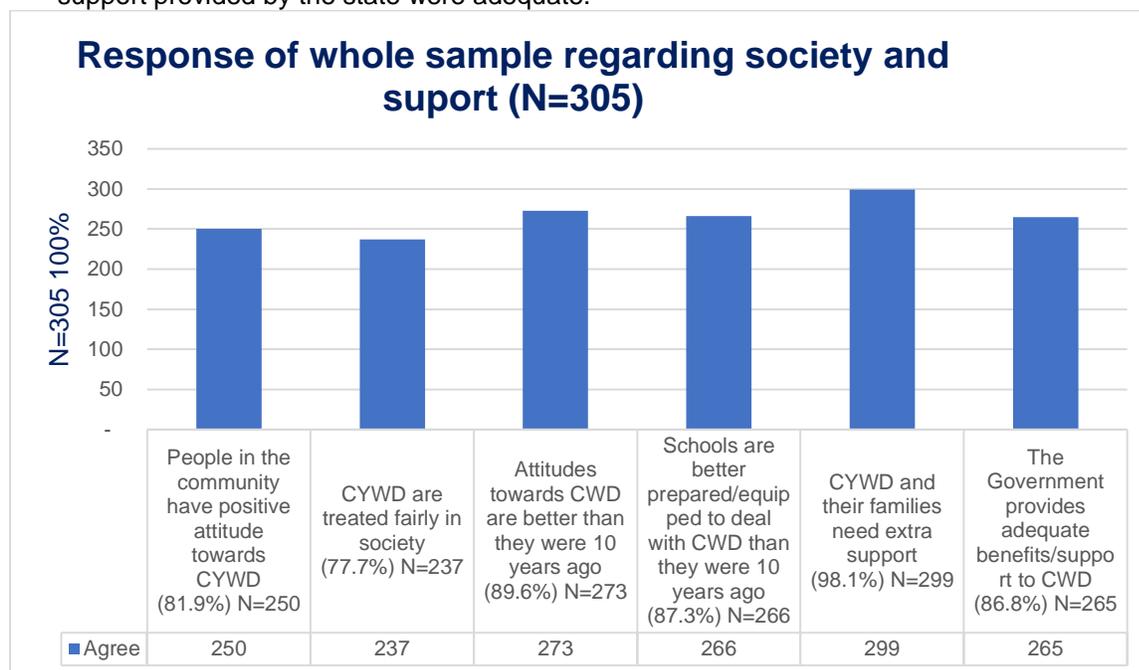
Comparisons and contrasts are drawn between the opinions of those families that have children and youth with disabilities (n=17) and those that do not (n=288). Chi-square tests were carried out with regard to the responses across the four categories of these two groups to identify whether any statistically significant differences exist. The data for each statement is presented. The caveat is that the number of respondents who were parents of children and youth with disabilities is small – it is therefore essential that suggestions within this data set are compared with the qualitative data gathered in the focus groups with families and individuals with disabilities.

3.4.1 Society and support

Respondents were asked their opinions on the following statements:

- (i) People in the local community have a positive attitude towards CYWD.
- (ii) CYWD are treated fairly in society.
- (iii) Attitudes towards CYWD are better than they were 10 years ago.
- (iv) Life is better for CYWD and their families than it was 10 years ago.
- (v) CYWD and their families need extra support.
- (vi) The state provides adequate benefits for CYWD.

(a) **All respondents:** Respondents' attitudes with regard to societal attitudes and support were overwhelmingly positive and supportive of the current situation. Over three quarters of respondents felt that CYWD were treated fairly both in society as a whole and within their local communities. Almost 90 per cent of respondents felt that attitudes towards CYWD had improved over the last decade, and that life was now better for these children and their families. Almost all respondents acknowledged that CYWD needed extra support; however, over 85 per cent of respondents felt that the benefits and support provided by the state were adequate.

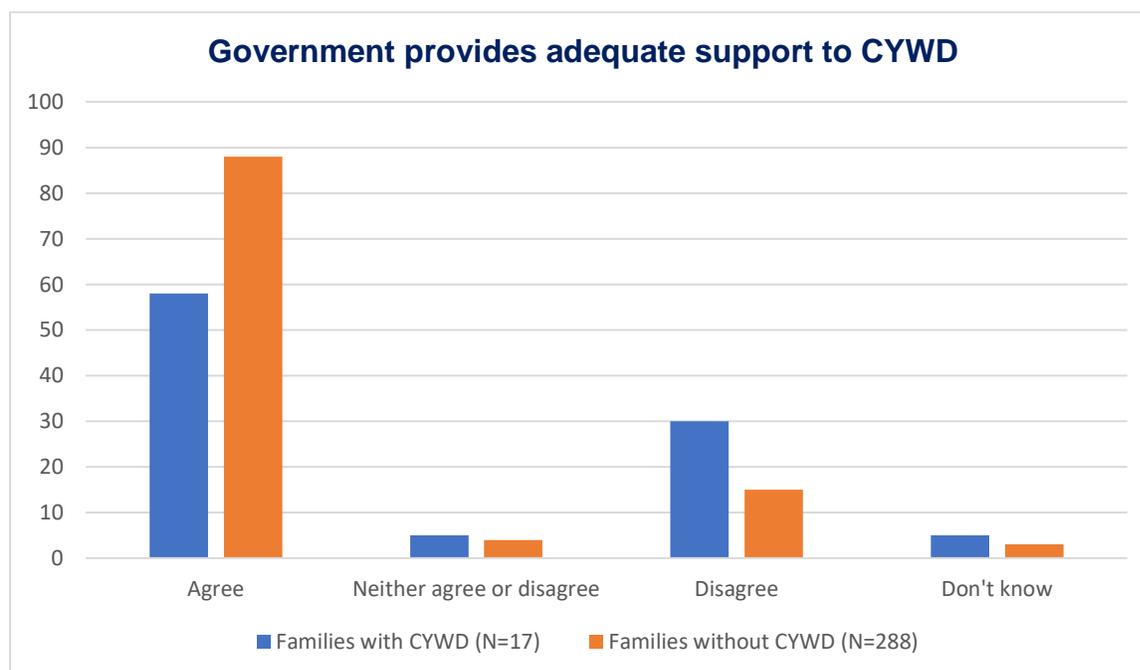


(b) Comparison between families with and without CYWD

Families with and without CYWD held differing opinions on a number of these statements:

- While over 80 per cent of families without CYWD felt that local communities had a positive attitude towards CYWD, this view was shared by just over 60 per cent of families that had such children.
- Responses were similar with regard to the statement that CYWD are treated fairly in society, in which families living with such children were less positive.

Almost 30 per cent of families living with CYWD disagreed with this statement, compared with approximately 15 per cent of families without such children. There was agreement that attitudes towards CYWD are better than they were 10 years ago, and that life is better for CYWD and their families than it was 10 years ago. There was almost unanimous agreement also with the statement that CYWD and their families need extra support. However, there was a statistically significant difference between the two groups with regard to the statement that the state provides adequate benefits for CYWD (see Figure below). While almost 90 per cent of families without CYWD agreed with this, with fewer than 7 per cent disagreeing, the picture was much more mixed for those living with such children: fewer than 60 per cent agreed and almost 30 per cent disagreed.



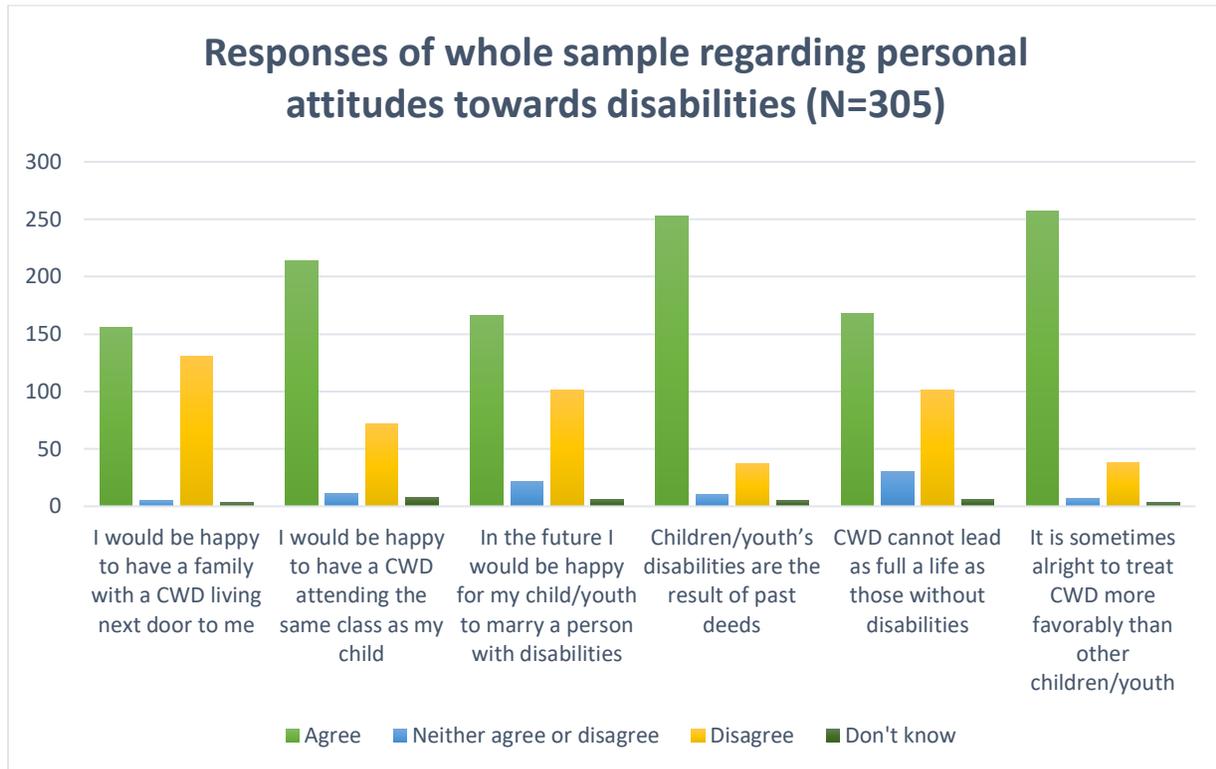
3.4.2 Personal attitudes towards disability

Respondents were asked their opinions on the following statements:

- I would be happy to have a family with a child with disabilities living next door to me.
- I would be happy to have a child with disabilities attending the same class as my child.
- In the future, I would be happy for my child to marry a person with disabilities.
- Children/youth's disabilities are the result of past deeds.
- CYWD cannot lead as full a life as those without disabilities.
- It is sometimes alright to treat CYWD more favorably than other children.

(a) **All respondents:** Attitudes were mixed with regard to the statement I would be happy to have a family with a child with disabilities living next door to me, with just over half of respondents (n=156, 51.3 per cent) agreeing, but a large minority (n=131, 42.8 per cent) saying they would not be happy with this situation. Responses to the statement In the future, I would be happy for my child to marry a person with disabilities were also mixed, with 166 respondents (54.4 per cent) agreeing and 101 respondents (33.2 per cent) disagreeing. Responses to the statement CYWD cannot lead as full a life as those without disabilities elicited similar responses: 55 per cent of the sample (n=168) agreed that such children's lives and experience were restricted, while 33 per cent (n=101) disagreed. Respondents

were more positive to the statement “I would be happy to have a child with disabilities attending the same class as my child”. Over 70 per cent agreed with this, while just under 30 per cent disagreed. There was even higher agreement within the sample to the statement “It is sometimes alright to treat CYWD more favorably than other children”: over 90 per cent (n=275) agreed with this. There was also high agreement to the statement that children’s disabilities are the result of past deeds within a Christian community like Rwanda. Over 80 per cent of respondents (n=253, 82.8 per cent) agreed with this, with only 12 per cent (n=37) feeling that this was not the case (see Figure below).



(b) **Comparison between families with and without CYWD:** There was high congruence between the personal attitudes of families with and without CYWD.

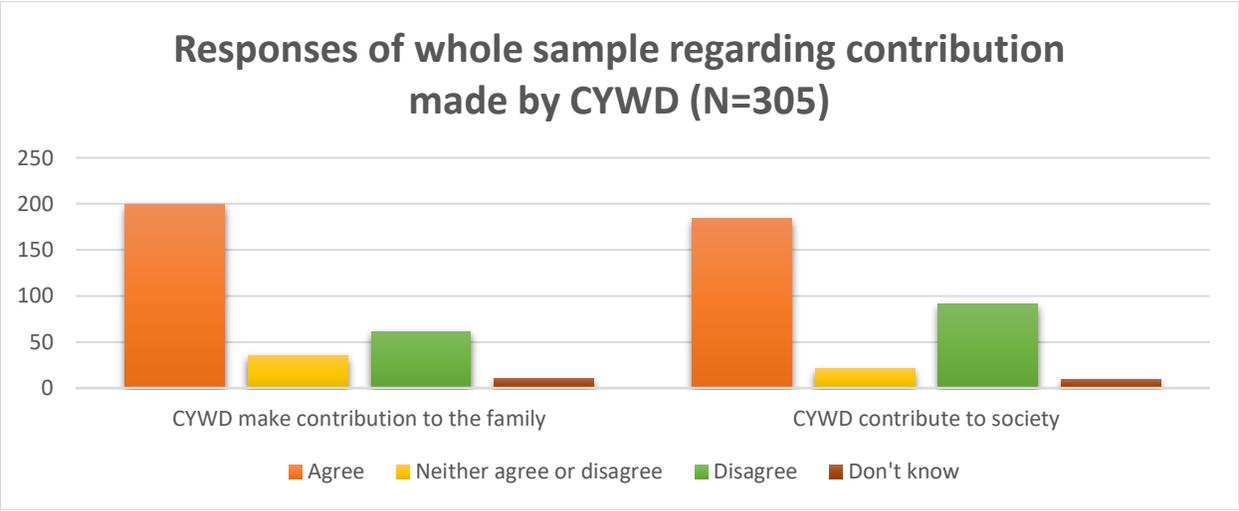
- Almost 50 per cent of families with CYWD stated that they would be unhappy to have a similar family living next door;
- Almost 30 per cent would be unhappy to have a child with disabilities attending the same class as their child;
- Attitudes between the two groups regarding the reason for children’s disabilities were almost identical.

3.4.3 Contribution

Respondents were asked their opinions on the following statements:

- CYWD make a positive contribution to the family.
- CYWD contribute to society.

(a) **All respondents:** Over 65 per cent of respondents agreed with the statement that CYWD make a positive contribution to the family, while about 20 per cent disagreed; and over 60 per cent agreed with the statement that CYWD contribute to society, with almost a quarter of respondents disagreeing (see Figure below).



(b) Comparison between families with and without CYWD

Again, there was high congruence between families with and without CYWD, with no statistically significant differences identified between the responses of the two groups to these statements about the contribution made by CYWD.

3.4.4 Education and inclusion

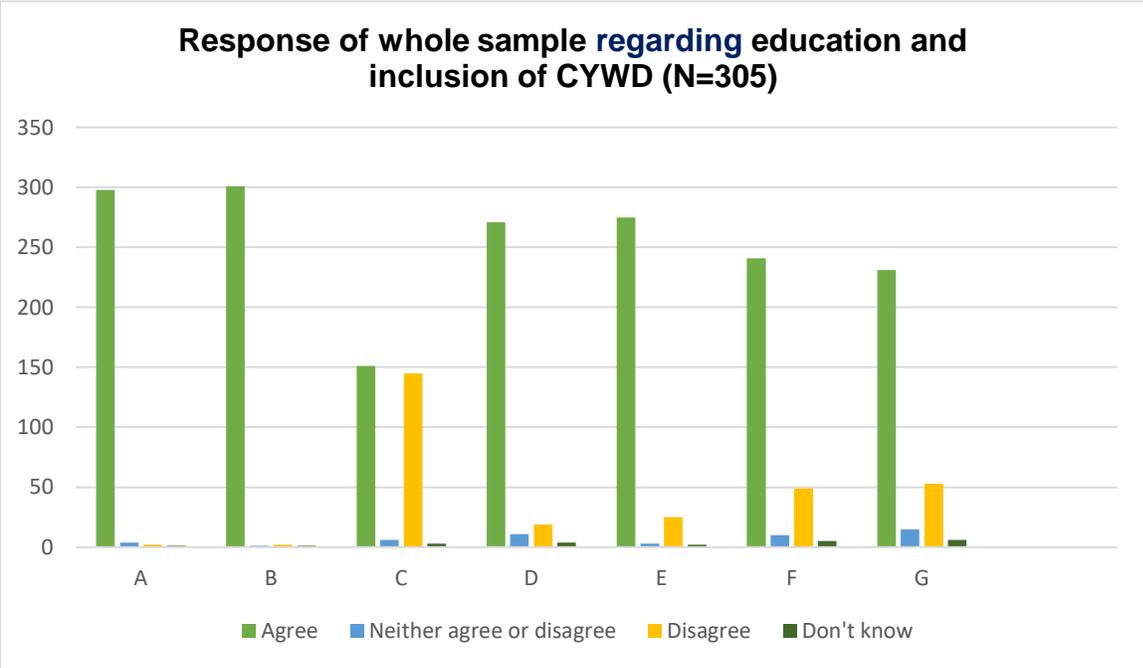
Respondents were asked their opinions on the following statements:

- (i) All children should go to school, regardless of their needs or any disability.
- (ii) CYWD benefit from attending school.
- (iii) CYWD should attend the same schools as other children.
- (iv) All CYWD should attend special schools and not general mainstream classes.
- (v) Schools are better prepared/equipped to deal with CYWD than they were 10 years ago.
- (vi) CYWD should be encouraged and supported to play with other non-CYWD.
- (vii) When CYWD leave school, they have the same employment opportunities as their peers.

(a) All respondents: There was almost universal agreement with three of the seven statements in this section:

- CYWD benefit from attending school (n=301, 98.6 per cent)
- All children should go to school, regardless of their needs or any disability (n=298, 97.6 per cent)
- Schools are better prepared/equipped to deal with CYWD than they were 10 years ago (n=275, 90.3 per cent).

Over three quarters of respondents also agreed with the statements that CYWD should be encouraged and supported to play with other non-CYWD (n=241, 79 per cent) and that when CYWD leave school, they have the same employment opportunities as their peers (n=231, 75.8 per cent). Responses to the final two statements in this section were somewhat contradictory. With regard to the statement that CYWD should attend the same schools as other children, there was an almost equal split within the sample, with 152 respondents (49.9 per cent) agreeing to this and 145 (47.5 per cent) disagreeing. However, with regard to the statement that all CYWD should attend special schools and not general mainstream classes, there was high agreement, with 271 respondents (88.7 per cent) indicating that they believed this to be appropriate. It is difficult to reconcile these two standpoints.



- A: All children should go to school, regardless of their needs or any disability
- B: Children with disabilities benefit from attending school
- C: Children with disabilities should attend the same schools as other children
- D: All children with disabilities should attend special schools and not general mainstream classes
- E: Schools are better prepared/equipped to deal with children with disabilities than they were 10 years ago
- F: Children with disabilities should be encouraged and supported to play with other non-CYWD
- G: When children with disabilities leave school, they have the same employment opportunities as their peers.

(b) Comparison between families with and without CYWD

There was high congruence between families with and without CYWD, with no statistically significant differences identified between the responses of the two groups to these statements on education and inclusion. With regard to the statement CYWD should be encouraged and supported to play with other non-CYWD, the parents of such children were in 100 per cent agreement, as compared with just over three quarters of households without CYWD. The contradiction identified above, regarding where CYWD should go to school, appears even more marked in the positions held by families of such children. While over 70 per cent of such families held that CYWD should attend the same schools as other children, they were almost unanimous in the view that all CYWD should attend special schools and not general mainstream classes. It is unclear if the responses to these two statements is indicative of some confusion regarding inclusion, or of a problem within the data collection process.

3.4.5 Protection

- Respondents were asked their opinions on the following statements:
- (i) CYWD are the subject of jokes or unacceptable or negative comments.
 - (ii) CYWD are more likely to be the victims of bullying.
 - (iii) CYWD are more vulnerable to physical and sexual abuse.
 - (iv) CYWD are more likely to be neglected.
 - (v) It is sometimes necessary to leave a child with disabilities in the house alone.
 - (vi) It is sometimes necessary to punish a child with disabilities for misbehavior.

- (a) **All respondents:** Almost two thirds of respondents did not believe that CYWD are the subject of jokes or unacceptable or negative comments, with just 31.7 per cent (n=97) feeling that this was the case. Just over half of respondents (n=153, 50.1 per cent) disagreed with the statement that CYWD are more likely to be neglected. However, higher numbers of respondents felt that CYWD are more likely to be the victims of bullying (n=344, 59.8 per cent), and that CYWD are more vulnerable to physical and sexual abuse (n=169, 55.5 per cent). Over 60 per cent of respondents (n=187, 61.2 per cent) disagreed with the statement that it is sometimes necessary to punish a child with disabilities for misbehavior, and over 80 per cent of respondents (n=255, 83.5 per cent) disagreed with the statement that it is sometimes necessary to leave a child with disabilities in the house alone.
- (b) **Comparison between families with and without CYWD:** Almost half of families with CYWD felt that such children are the subject of jokes or unacceptable/negative comments; over 80 per cent felt that such children were more likely to be bullied. This stands in contrast to the families without CYWD, where these views were held by just 25 per cent and 60 per cent, respectively. A slightly higher percentage of families that included CYWD felt it could be appropriate at times to punish such children for misbehavior (47.1 per cent compared with 33.7 per cent). With regard to the other statements, there was again close congruence between both subsets of the sample.

4.5 CYWD – comparison of attitudes of respondents living near to CYWD with those who do not

The case survey team considered the possibility of comparing the attitudes of families living near to CYWD (i.e., within the same sectors as those respondents who have CYWD) with those who did not; this was to explore whether proximity to such families had an impact on attitudes. Unfortunately, as only a sample of households from each sectors was surveyed, it was impossible to identify whether any of the households within each sectors that did not participate in the survey included CYWD or not. Therefore, any inferences drawn from such comparisons would be unsafe and based on false premises.

4.6 CYWD – comparison of attitudes of male and female respondents

The responses of male respondents (n=105) and female respondents (n=200) were compared. There was high congruence between male and female respondents, with a significant difference only in relation to one statement: that schools are better prepared/equipped to deal with CYWD than they were 10 years ago. More than twice the percentage of males disagreed with this statement than females (4.7 per cent compared with 2.2 per cent) and female respondents expressed greater uncertainty, with 4.4 per cent saying they do not know, compared with 0.9 per cent of male respondents.

4.7 CYWD – comparison of attitudes of respondents by age

The attitudinal responses were also analyzed using respondents' age as a variable. Respondents were grouped into three subsets:

- Under 40 years (n=135, 44%)
- 40–59 years (n=127, 42%)
- 60 years and above (n=43, 14%)

Statistically significant differences were identified with regard to seven statements across all five domains.

4.7.1 Differences in attitudes regarding society and support by respondents' age

There were statistically significant differences between responses to two statements in this domain. With regard to the statement that attitudes towards CYWD are better than they were 10 years ago, respondents aged 40 to 59 years expressed higher agreement than both younger and older respondents.

4.7.2 Differences in personal attitude towards disability by respondents' age

In respect of personal attitudes, respondents aged 60 years and above were less positive towards the statement that I would be happy to have a family with a child with disabilities living next door to me, with just over 40 per cent agreeing, and 50 per cent disagreeing. This was the reverse of the two younger groups, where over 50 per cent agreed and about 40 per cent disagreed.

4.7.3 Differences in attitudes towards the contribution made by CYWD by respondents' age

Again, in this domain, respondents aged 60 and over were less positive, with about a quarter disagreeing with the statement that CYWD make a positive contribution to the family; the figure for the other two subsets is less than 20 per cent.

4.7.4 Differences in attitudes towards the education and inclusion of CYWD by respondents' age

No older respondents disagreed with the statement that schools are better prepared/equipped to deal with CYWD than they were 10 years ago.

4.7.5 Differences in attitudes towards the protection of CYWD by respondents' age

There were statistically significant differences between the three subsets with regard to the three statements within this domain. Concerning the statement that CYWD are the subject of jokes or unacceptable or negative comments, a much higher percentage of older respondents agreed: 45.1 per cent of respondents aged 60 years and older, compared with just under 32 per cent of those aged 40–59 years and just over 27 per cent of under 40s. There was also much less expressed disagreement with this statement from the older group (about 46 per cent, compared with about 65 per cent from the other two subsets).

The situation was somewhat reversed for the statement that CYWD are more likely to be the victims of bullying. Here, younger respondents were in greater agreement with the statement (63 per cent, compared with under 59 per cent for those aged 40–59 years and under 54 per cent for those 60 years and over). They were also less equivocal, with just 2.4 per cent saying they neither agreed nor disagreed. This contrasts sharply with the 3.4 per cent of those aged 40–59 years and 14.6 per cent of those aged 60 years and over who gave this response. Younger respondents were also in greater agreement with the statement that CYWD are more vulnerable to physical and sexual abuse; almost 60 per cent of them agreed, compared with around 50 per cent of the other two subsets.

4.8 CYWD – impact of education level on attitudes

In order to explore whether respondents' education level had any impact on their attitudes towards CYWD, the responses of the least educated subset of the sample – those who had received no formal education (n=185, 60.5 per cent) – were compared with those who were most highly educated – those who were educated to degree or postgraduate levels (n=19, 6.2 per cent). Their responses to the 21 Likert scale statements were compared. There were no significant differences for the domains relating to Society and Support or Protection. However, significant differences were identified with regard to nine statements across the remaining three domains, which are discussed here.

4.8.1 Differences in personal attitude towards disability between respondents with no formal education and those educated to degree/postgraduate level

Significant differences were identified in five of the six statements in this domain. In respect of the statement that I would be happy to have a family with a child with disabilities living next door to me, those who were more highly educated were much more positive, with 77.7 per cent agreeing (as compared with 48.6 per cent of those with no formal education) and only 16.7 per cent disagreeing (compared to 46.6 per cent) (see Figure 32). More highly educated respondents were also more positive to the statement I would be happy to have a child with disabilities attending the same class as my child: almost 90 per cent agreed (compared to just over 67 per cent) and only just over 8 per cent disagreed (compared to over 31 per cent).

More highly educated respondents were again more positive about the ability of CYWD to lead a full life. With regard to the statement that CYWD cannot lead as full a life as those without disabilities, the responses were equally balanced from more highly educated respondents, with half agreeing and disagreeing, while only about a more than half of respondents without formal education third agreed and almost one , while two third disagreed. The responses were more equally balanced from those without formal education, with just under half agreeing and disagreeing. A more mixed picture was presented for the statement that In the future, I would be happy for my child to marry a person with disabilities. More highly educated respondents were less clear here in their responses, with 16.7 per cent stating that they did not know. Those without formal education were much clearer, with only 1.4 per cent giving this response.

There were significant differences in respondents' understanding of why children had disabilities. Over 85 per cent of those without formal education felt that this was the result of past deeds, with only about 10 per cent disagreeing. This contrasted sharply with the responses from those educated to degree/postgraduate level, where only just over half of the respondents agreed, and almost 30 per cent disagreed.

4.8.2 Differences in attitudes towards the contribution made by CYWD between respondents with no formal education and those educated to degree/ postgraduate level

Statistically significant differences between the responses of the two sub-groups have been identified about two statements within this domain. Again, those respondents who are more highly educated gave more positive responses. With regard to the statement that CYWD make a positive contribution to the family, 75 per cent of those educated to degree/postgraduate level agreed, with only 5.6 per cent disagreeing. For those with no formal education, the figures were 63.8 per cent agreeing and 19.5 per cent disagreeing. With regard to the statement that CYWD contribute to society, over 80 per cent of those more highly educated agreed, compared with just over half of those with no formal education; and while over 25 per cent of this latter group felt that such children did not contribute to society, this view was held by only one respondent from the degree/postgraduate sub-group.

4.8.3 Differences in attitudes towards the education and inclusion of CYWD between respondents with no formal education and those educated to degree/postgraduate level

Statistically significant differences between the responses of the two sub-groups have been identified about the two statements within this domain. More highly educated respondents were more skeptical that schools are better prepared/equipped to deal with CYWD than they were 10 years ago, with just under 70 per cent agreeing (compared to over 90 per cent of those with no formal education) and 16.7 per cent disagreeing (compared with 2.0 per cent). More highly educated respondents also felt more strongly that CYWD should be encouraged and supported to play with other non-CYWD, with only just over 5 per cent of respondents disagreeing, compared with almost 20 per cent of those without formal education.

4. CASE SURVEY FINDINGS: QUALITATIVE DATA

4.1. Survey orientation

As with the quantitative material, qualitative data were collected in accordance with the methodology agreed with and approved by REFAC Coordination. The locally employed enumerators were trained to conduct the focus groups and the informal interviews by University of Northampton researchers during September 2020. The data were gathered during September 2020 and transcribed data were sent to the REFAC team in September 2020.

4.2 Survey instruments

This section of the report presents narrative data from both the focus group discussions and the interviews, undertaken across the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge in September-September 2020. Qualitative data were obtained through focus groups and interviews. These were convened to enable interested parties to discuss their experiences and overview the provision made for CYWD in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge. Ten focus groups were conducted with service users and providers distributed across urban and rural districts of the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge, including some nominated key personnel involved with CYWD.

The data from these processes were subjected to categorical coding to identify recurring and consistent themes that could provide insights into the lives and experiences of CYWD and their families in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge to inform a discussion of the situation for children with disabilities in their communities. In addition to providing professionals, parents and children opportunities to express their views and thereby inform the research, the data obtained from these focus groups enabled the case survey team to extend their interpretation of the findings of the national survey and to clarify meaning in respect of specific issues that were seen to be important in the provision made for CYWD.

Data were collected from both urban and rural districts across the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge. Focus groups and interviews were managed by enumerators who had received training for this purpose. Field notes and audio recordings were maintained, transcribed, translated and forwarded to the lead consultant for analysis. To maintain consistency with the presentation of the quantitative data obtained through the questionnaire survey, the findings from the qualitative data will be presented in relation to the three areas of knowledge, attitudes and practices. This enables the differing perspectives of respondents from the focus groups to be identified and commented upon to provide a triangulated data overview of the situation in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge.

In the analysis that follows, indicative verbatim commentaries from various stakeholders are inserted to illustrate the views held by various participants. Whilst these cannot be regarded as representative of a widespread position on any single issue regarding CYWD, they are nevertheless useful in providing an indication of the varying views held on key matters of practice and provision and in several places offer confirmatory evidence in support of questionnaire findings. The illustrative extracts are identified by 'NC' (Narrative Comment) and are placed in italic script.

4.3 Knowledge

Knowledge about disability in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge appears to be largely invested in professionals who have responsibility for the development and implementation of policy or the delivery of educational, social or health services. Amongst parents and children, the knowledge about disability, its causes and implications is limited and in some cases misinformed ("*Children who cannot walk, are limp or don't have hands*" NC). The association of 'disability' with mainly physical characteristics thus provides definite supporting evidence to the quantitative data obtained.

Service providers also are inclined to focus upon disability in its physical or sensory manifestations, identifying deficits that impede the abilities of individuals to function effectively within the communities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge. ("*We can most tell from the way that a child responds to visual or sound stimuli. And if a child had a physical disability then we can tell when*

we look at them. And when a child has a cognitive disability we can tell from the way they respond to our teaching” NC).

Responses given in the focus group sessions and interviews by service providers indicate that a standardized means of assessing the needs of individuals described as disabled is not currently being employed (“...it is difficult because an assessment tool or a screening process needs to be in place like the rapid neurodevelopment assessment but these are only available in the 12 schools with SEN program and some ECCD centers” NC). There is instead an emphasis on the physical attributes of individuals rather than a holistic interpretation of need being the norm (“children who are able and normal can do a lot in terms of their six senses but disability is when the children have impairment in one or two senses. And they are not able to do as well as the other children. The common disabilities are physical ones like hearing impairment, visual disabilities and even psychological disabilities” NC).

Disability is seen in limited terms as a child deficit and little consideration was given in responses to environmental influences or social factors; this echoes the key findings from the quantitative data presented. Whilst little attention was given to children with intellectual disabilities, it was implied in many responses that those children with physical or sensory disabilities were likely to have difficulties accessing learning (“Blindness is the most challenging because for all the other disabilities they can at least see the world. But a child who cannot see is forever living in darkness” NC). There were similar responses from participants in the Districts of the City of Kigali, though this group did identify conditions such as autism spectrum disorders and intellectual disabilities as an area of concern (“...some of the greatest challenges being developing knowledge and skills in dealing with autism and intellectual disabilities and training teachers in these areas” NC).

Representatives from NGOs considered negative attitudinal issues to be an influential factor in the interpretation of disability and the labelling of children (“our thinking and our attitude makes us think about what it means to be disabled...When we talk about disabilities, attitude is a very important factor. So, having a law in place is extremely important because with a law in place I feel that a change in attitude will follow” NC). They similarly believed that environmental factors that inhibit access to learning or to the local community were significant in exacerbating disabling conditions (“...what we need to do is to provide job opportunities for children with disabilities because forget about those who don’t have an education, even graduates don’t get employed. Because parents spend so much in educating their children who have disabilities and when they finally do graduate they are ignored and often land up without a job. And they cannot go back to their village and work on their farms because they don’t have that capability. So in such situations I think the government should step in and do something about it” NC).

Parents of children and youth with disabilities and also those who did not have a child with disabilities tended to have a narrow understanding of disability generally formulated upon the basis of limited engagement with people with disabilities (“I don’t know anyone like that. All I know is what I have seen on TV” NC). As would be expected, the parents of children with disabilities were knowledgeable about their own child’s conditions and the implications of this upon daily life (“I would like to talk about my son _____ [name removed]. He is having problems with vision, hearing and also faces difficulty while walking. The biggest challenge that he faces is coping up with his learning because he is not able to read or write properly and on top of that he does not feel the dotted book properly. Because of this his teachers are facing problems in identifying his needs and he is lagging behind compared to others” NC). However, beyond their own child both their knowledge and their experience were limited.

Those parents who had no experience of bringing up a CYWD focused upon physical and sensory impairments when asked to define disability and most stated that they had either no or limited experience of CYWD (“I don’t think I will be able to say anything. I think it’s basically those children who need extra attention. If children are limp or deaf, then we have to take care of them but normal children don’t need extra attention” NC). Children, both with and without disabilities, had a similar interpretation of disability to that given by adults, and many had had similarly limited opportunities to engage with their disabled peers. When asked about the causes of disability, responses fell into four categories. The first of these can be described as a fatalistic belief that disability resulted from bad karma with disability visited upon the child because of events in a previous life involving either the child or his parents (“Some children are born with a disability because of their destiny” NC). This belief was common not only amongst parents and children

but also held by several of the professionals involved in the focus groups – observations that are supported by the questionnaire data. A second response related to inadequate neonatal care or poor diet during pregnancy (*“Due to improper diet during pregnancy or the age of the mother or it can be acquired due to an accident or a disease. I think we should also work on preventive measures for disabilities”* NC). This was closely aligned to a perception that in some instances the use of substances, including tobacco, alcohol or drugs, was a likely cause of having a CYWD (*“Some take drugs due to which their brain gets damaged”* NC).

A final category of response identified poor hygiene, including that sometimes experienced in hospitals, as a contributory factor (*“I think it’s due to negligence on the hospital’s side also. They told us that the due date was quite far and so we should go back home. But as soon as we reached home my wife delivered the baby when she was in the toilet. I think the hospital staffs are very careless”* NC). When asked to consider the impact of having a CYWD upon family life, most respondents recognized that this situation was likely to cause stress to parents and families (*“I think many of us also face challenges in coping up with the community. We are being neglected on many occasions and in many fields especially while dealing with people who have negative thoughts on our children like when people say that children with disability will bring bad luck and all”* NC).

The perceptions of many respondents indicated that they are sensitive to the challenges faced by families with a CYWD and their understanding of the potential impact upon their daily existence was largely in accord with those views expressed by parents living with disability. Reference to the time required to manage a CYWD’s daily routine, and the focus upon high levels of personal care was a feature of the discussion in all focus groups (*“There are a lot of challenges for that family, one of which is that no matter where they go there will have to be someone to take care of the child. Another is that you won’t be able to live or die in peace because you will always be worried about the well-being of the child”* NC). Such views are consistent with evidence drawn from the HSQ.

Some respondents recognized that having a CYWD would cause a financial strain on families, and that in some instances the opportunities to work in paid employment would be severely constrained (*“As a parent I think most of the children with disability come from poor families, which further weighs down on our income. I feel that we are not able to provide much resources and facilities for our children”* NC). Asked about sources of information about disability, most respondents stated that they obtained information through the media, or in some instances through NGOs as well as NCPD (*“From the news and from the hospitals also”* NC). Similarly, very few respondents were aware of any national or international policies or legislation that might inform issues of disability. This presented a further confirmation of findings obtained from the questionnaires.

4.4. Attitudes

There was a consensus amongst respondents in all focus groups and interviews that CYWD should attend school. The majority believed that wherever possible this should be a mainstream school, where Children and youth with disabilities could learn alongside their peers who do not have disabilities. Emphasis was placed upon the need for CYWD to socialize and to learn from their peers (*“If they befriend each other and help one another it will be good for them. The parents of the children with disability will also worry less”* NC).

Some parents of children who do not have disabilities expressed a view that attendance should be in segregated provision (*“They should be classified according to their disability and put in a school that is specialized in that disability”* NC). When asked to elaborate upon their reasons, these were either because Children and youth with disabilities would demand too much teacher time or that there might be a danger that their own child would contract some aspect of the disability from their classmates (*“I feel that there will be a risk of contagion”* NC). This latter comment further suggests that there is a poor understanding on the part of a minority of respondents of the etiology of disability.

Most respondents believed that providing opportunities for children to play together was important and that this could result in improved social opportunities and some improvements in learning (*“Yes, the children with disabilities can learn from the children without disabilities”* NC). Those who did have concerns were generally anxious for the safety of Children and youth with disabilities, though again some parents

expressed a view that their children might be in danger of contracting illness (disability) from their disabled peers (*"You will be scared that your children might contact their diseases"* NC)

Concerns were expressed that CYWD were often the subject of bullying in schools and in public (*"Normal children tell the children with disabilities to not come near them because they feel that they might get the disease and shoo them away by calling them names"* NC) and (*"There are chances that the able children will look down on the children with disabilities and end up insulting and bullying them"* NC). Those CYWD who participated in the research reported having been laughed at and in some instances physically bullied in schools. Equally of concern were the number of respondents who suggested that CYWD were particularly vulnerable in social situations to the possibilities of falling victim to sexual abuse (*"She will be vulnerable to sexual assault from other men"* NC).

There was a general recognition that CYWD require greater resourcing than others and a consensus that this should be provided and that the government often provided a good service in supporting families (*"I have a friend whose child is disabled, and he is surveying in this school. She doesn't have any one to support her son and she can't help as she is also disabled. In such cases I think the Government support helps a lot and it should be given to such people who are in need"* NC).

4.5 Practices

There was a consensus amongst respondents that practice is to some extent inhibited by difficulties of gaining access to services in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge (*"I think the greatest challenge that we face as of now is that we are not able to provide them the right medical support. If we consider the developed countries, they have occupational therapy for children with disabilities, but we don't have that in our country. Our children even face difficulty in reading Braille due to which parents and teachers face difficulty in guiding them"* NC). These views confirm the findings emerging from the questionnaires. Conversations with key informants suggest substantial progress has been made in the provision of services; both these and data from the questionnaires illustrate that parents of CYWD, and, especially those in isolated rural locations, have difficulty in identifying and accessing these facilities.

This situation is further impacted by poor infrastructure, resulting in limited access to some buildings and other facilities (*"When children have to use wheelchairs, they cannot get around easily. I think we are lacking in disable friendly physical structures. We need to construct ramps in schools that have children with disability, and paths for blind children which will enable them to be independent using canes and also make sure that the drains or any other holes are covered"* NC).

Many parents also expressed the view that health service professionals are not well trained to either assess or provide support to families who have a child with a disability, and that this has a detrimental effect upon the services they receive (*"I don't think they are well trained. It's really sad when you go for treatment for two consecutive years and then they finally tell you that there is nothing they can do for your child. They even went so far as to tell me that it was own karma and that I should learn to deal with it. I am never taking my child to the hospital again"* NC).

A widely held view was in evidence regarding the importance of educating and socializing CYWD. There was evidence in the narratives of the effectiveness of mainstream schools in this regard, although an element of pragmatism was noted in several cases (*"I think that they should first be put in specialized schools to learn the basic skills and then when they are able they should be put in mainstream schools"* NC). There was a view amongst parents and children that teachers were willing to work with CYWD, but that teachers have not received sufficient training to be effective in this area (*"Teachers here need to be well trained but what I heard and what I know personally is that they are not trained to teach children with disabilities. Almost all the teachers get trained from teacher training colleges and have had no other special trainings"* NC).

Service providers believed that some teachers in the specialist schools were better trained than their counterparts in mainstream provision (*"I feel that the children with disability should attend specialized schools because teachers are better suited to deal with them"* NC) and (*"If they went to specialized schools then all the students will be the same and it will be easier to interact amongst themselves"* NC). However, the CYWD who contributed to the focus group discussions believed that their teachers served them well,

despite recognizing that they had difficulties in fully understanding their needs (“*They teach equally like those who can see with a hope to make us same like them yet more time is consumed while teaching visually impaired and someone who can’t hear*” NC). These observations are aligned with questionnaire data and offer evidence of a thematic emphasis on training and development, as indicated in the Recommendations.

A concern was expressed by some parents and service providers that the pace of learning in schools was too fast for children with disabilities and that this would cause them and the teachers difficulties in some classrooms (“*If it is a general teacher and they have a child with disability in their class of 40 students, then when the teacher is concentrating on that one student, the 39 students get neglected. And if the teacher is concentrating on the rest of the class, then they can’t focus on that child. Then there is the problem with resources because that child needs something extra*” NC).

Only one focus group, conducted with NGOs, suggested that rural areas were less favorably served than urban locations (“*The facilities in the rural areas are less compared to the urban areas*” NC). The responses from paired focus groups (for example, parents from urban and rural environments) provided no evidence of significant differences of attitude or practices. The qualitative data from both the focus groups and the individual interviews reveal some significant correlations with the findings of the questionnaires. Each data set provides substantive evidence that there are several comparable thematic areas for potential scrutiny in the field of CYWD. These are examined in the next section of this report.

5. DISCUSSION

5.1 Introduction

This section of the report provides an overview and commentary on the data generated during the fieldwork phase of the survey. The intention is to provide a discussion that offers both a reflection on the cumulative data obtained, highlighting its key themes in relation to CYWD, and a stimulus for ongoing conversation and debate amongst key stakeholders within the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge.

The survey has sought to capture the following aspects:

1. Generation of knowledge regarding (a) the characteristics of CYWD from the perspectives of service users and providers; (b) a review of legislation, policy and literature with regard to Children and youth with disabilities, both national and international; and (c) information relating to key services to support CYWD.
2. A comparison of attitudes from a diverse sample of respondents.
3. Identification of effective practices that best support CYWD in a range of service contexts in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge.
4. A set of recommendations for potential future developments in support of CYWD in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge.

Of each of these four elements, the focus is placed principally on the characteristics of CYWD from the perspectives of service users and providers. The first part of this section covers a general overview of the current position regarding CYWD in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge; identification of both achievements and barriers in provision and possible priorities for future development; and recommendations to key stakeholder groups working with CYWD and their families. The second part of the section comprises a series of reflections on the data gathered to consider each of the above issues in the light of the literature relating to both international themes concerning CYWD and their manifestation in the results obtained.

5.1.1 Overview of Knowledge, Attitudes and Practices relating to CYWD in The Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge

(a) Knowledge

The survey revealed that knowledge regarding CYWD was extremely limited. This applied to both legislation and provision of relevant services for this group of children. It also applied to the respondent's knowledge regarding referral routes for seeking advice support and access to provision for CYWD. This situation was apparent for both families with CYWD and those without. Those services with which respondents were most familiar were almost exclusively connected to the provision of medical support. The term 'disability' was generally defined in narrow terms as representing only those individuals who have severe physical or sensory impairments, with a consequent tendency to marginalize those from other groups. Only half of the respondents indicated that they understood the term 'intellectual disability', about the same proportion who recognized wearing glasses as a disability. This has implications for service delivery, notably that there is an emphasis primarily on providing support predominantly to those with a 'visible' disability. This situation is exacerbated by the previously mentioned lack of accessible, reliable and user-friendly information, with most respondents suggesting that they gain insights into disability through television, although the origins and reliability of such information could not be ascertained.

(b) Attitudes

For the population in general, attitudes were shaped in part by the lack of knowledge, as previously indicated. Attitudes towards CYWD and their families were more positive among younger respondents (under the age of 60 years) and more highly educated respondents. For the latter, the data did not distinguish between those who had or had not received specialist training related to disability.

The absence of knowledge related to CYWD is a significant factor in the responses of the general population who did not perceive intellectual impairment as a disability. The data suggest that the general population overwhelmingly considered that CYWD were treated fairly. Moreover, they perceived CYWD to be vulnerable, with respondents stating they should receive appropriate levels of protection, and that their disability should not result in the use of punishment or isolation. In spite of such positive inferences regarding CYWD, it was apparent that a significant minority of families identified that they would not be happy to have a family with a CYWD as neighbors and that many would not want their child to marry someone with a disability, which may be a "divine curse". They also expressed reluctance to see their children educated alongside those who have a disability. A further negative perception was obtained from families of CYWD, who felt that the support that they received both in school and within their community was inadequate.

(c) Practices

In the general population, there was a consensus that educational and social provision for CYWD in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge was improving, and that the support provided by the state was adequate. However, families living with CYWD were less positive and felt that they received less support than they would wish. These families stated that most of the support that they received came from within their wider family circle and that they were isolated from other families living with CYWD. Helpful though this was, these families still considered this to be inadequate to meet their needs. A majority of families felt their CYWD would still be living at home with them at the age of 18, inferring their uncertainty about future prospects of independent living for their child.

5.1.2 Achievements and barriers

The data provide some evidence that there are a range of enabling factors that provide a platform for potential developments in support of CYWD in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge. It is important to recognize that these are at least inferentially associated with the overall national approach to supporting education and social welfare for all children in the country: this issue has been highlighted at various points in the literature and has been increasingly apparent during the last decade.

The survey team has chosen here not to emphasize the term ‘achievement’ as it implies summative measurement and would potentially detract from the efforts that have been made to improve the lives of Children and youth with disabilities and their families. It would also imply that the notions of educational and social inclusion comprise fixed points at which finite quantification can be undertaken. This, as the literature review indicates, is a reductionist perspective, which does not promote future action in this field. Instead, interrogation of these data suggests that there is a recognition by those in authority that there is a situation that requires attention in order to further improve the lives of CYWD and their families. This awareness is acknowledged at ministry level and by many service providers and thus connects implicitly with the views expressed by families of CYWD themselves in the questionnaires and narrative data.

Engagement with schools during the research process suggests that there is some confidence regarding the willingness to address issues of educational and social exclusion. There is also some evidence of an awareness of the need to provide disability-related professional development for key personnel working with CYWD, building on current developments.

However, such positive indicators are counterbalanced by omnipresent barriers, which co-incidentally are reflected in many other national settings worldwide. Principal amongst these is the diffuse understanding of the core issues that impact the lives of CYWD and their families. Recognition of these is inhibited by the aforesaid absence of accessible information and the consequent lack of cohesion and concerted action across essential support services. The data assembled in this report provide evidence of a need for action in a range of areas associated with CYWD.

6. RECOMMENDATIONS

6.1 Introduction

This final section uses the data obtained, additional field notes and observations, and the team’s intuitive insights regarding their immersion in these materials and background in CYWD policy and practice to present a set of recommendations. These are provided with some underpinning notes of caution on their purpose and usefulness.

Based on the analysis of data in the preceding sections, four target areas have been identified to which recommendations are directed, it is expected that the team’s projections will be amplified by other potential areas of development following subsequent conversations with key stakeholders. Further, there is a recognition that each recommendation is not mutually exclusive, with considerable synergy and interdependence between one or more being very apparent. Finally, they are presented in outline only, with a brief accompanying commentary: deliberation regarding specifics is a matter beyond the terms of reference of the survey undertaken.

6.2 Recommendations

6.2.1 Responses to systemic challenges and changes

- (i) Define clearly roles/responsibilities/structures (national, regional and local) for CYWD at policy and provision level.
- (ii) Establish a national policy for social and educational inclusion of CYWD.
- (iii) Recognize a multi-agency, inter-sectoral approach.
- (iv) Create greater public/professional awareness/understanding of CYWD by a national campaign.
- (v) Need for further research on emergent themes in CYWD policy and provision.

Provision for CYWD requires national leadership and exemplification. There needs to be concrete and visible policies and structures at the center, designed to establish a short-, medium- and longer-term strategy with an associated action plan (with prioritized objectives, outputs and indicators) to ensure that incremental development takes place in key areas identified. This process should be informed by inputs from all CYWD stakeholders. It should include an emphasis on integrated service provision and a national commitment to raising public awareness of CYWD. Each of these actions is regarded as a vital component in developing wider access to appropriate services by CYWD, as well as being aligned to accepted international approaches in inclusive provision.

In respect of future research/surveys, there is a pressing need to explore and develop, at a national level, the positive contributions that can be made by utilizing qualitative data-capture measures: these are likely to enable the voices of CYWD and their families to be more accurately represented. They can contribute more constructively to future policy deliberations by doing this.

6.2.2 Recommendations to the families with CYWD

- (i) Provide more visible and accessible support for CYWD and their families.
- (ii) Disseminate parent-friendly information on CYWD.
- (iii) Establish parent-to-parent groups (CYWD).
- (iv) Develop formal home–school links.
- (v) Create parent training opportunities related to CYWD.

The effectiveness of national, regional and local developments for CYWD (whether short-, medium- or long-term) will be most accurately evaluated by their impact on CYWD themselves, as well as the families they live with. The most important principle in ensuring that the quality and availability of provision is enhanced is that professionals (for example, teachers, health and social care workers) should be appropriately trained to provide interventions that are in accordance with state-of-the-art practice in the field. It is also essential that knowledge about services, and a clearly defined system of accessing them, needs to be made more visible at local and regional level. Schools are ideally placed to function as disseminators of this information.

6.2.3 Recommendations to the general population

- (i) Establish a CYWD awareness campaign for general population.
- (ii) Engage elders, heads of villages, religious leaders and other key local figures.
- (iii) Involve civil organizations/NGOs in a systematic and integrated way.
- (iv) Focus on enterprises/commercial sector as ‘CYWD Champions’.
- (v) Form ‘peer-support’ arrangements (CYWD and non-CYWD).

Inclusive systems for CYWD, now universally recognized as the optimum mode of structuring provision, can only thrive if whole communities recognize and engage with the challenges and possibilities that are afforded by their full inclusion. A starting point for this is the growth of a sense of national ownership of the issue as a whole, so that attitude change can take place. Exemplification elsewhere suggests that a catalyst for this is to raise awareness amongst the general population. Any changes will require a structured approach, with a recognition that such attitude shifts will inevitably be only apparent incrementally over time; this process is likely to be longer- rather than short- or medium-term. Any strategy will also need to incorporate ways of monitoring and measuring progress towards targets which might be several years in the future. The shorter-term gains also need to be subject to evaluation and successful practice identified, so that it can provide a stimulus for further efforts in support of CYWD.

6.2.4 Recommendation to the professional groups

- (i) Review initial teacher preparation to include a disability focus; inputs also need to be reviewed for health and social care training.
- (ii) Provide specialist training in disability (all associated professionals).
- (iii) Review in-service development/training of school leaders.
- (iv) Provide in-service training for existing teachers (whole-school development).
- (v) Establish inter-agency forum for CYWD professionals.

At the heart of all successful national initiatives to address the needs of CYWD and to promote their full social and educational engagement lies a trained and appropriately qualified workforce. This needs to start with general professional training. This should be directly linked to associated opportunities to examine current approaches in in-career development for all professional groups associated with CYWD. It is important, as recognized in ecological theory, that a widespread review of all training should include opportunities to reflect on the nature of inter-agency practice, so that a common agenda – especially in respect of attitudinal principles and their relationship to a shared approach to supporting CYWD – remain as a core aspect of the discussion.

7. Conclusion

This KAP case survey was commissioned by REFAC as part of the implementation of the “Active Civil Society for Inclusive, Equitable and Quality Education in Rwanda” Project funded by the Education Out Loud through Oxfam Ibis. REFAC strongly believes that the intention of the survey has been successfully achieved; this survey report being at the core of that success. The survey comprised five phases; the first phase scrutinized the existing literature on education of children and youth with disabilities in Rwanda; the second phase used three instruments to gather data from an agreed sample within the 5 Districts targeted in the project; the third phase comprised an interrogation of the data generated; the fourth phase provided a full draft of the final report for scrutiny by REFAC and Stakeholders; and the fifth and last phase constituted the delivery of a workshop, supported by appropriate resources, regarding the survey findings.

The survey has generated data that provide evidence on the KAP of education of children and youth with disabilities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge, primarily from the perspectives of families with children and youth with disabilities and those without. Key findings thus relate to both groups. In addition, data were secured from education policy implementers, education service providers and religious leaders. Data were secured using both quantitative and qualitative instruments: a household survey questionnaire, a focus group discussion tool and informal interviews with key individuals working in the field. Data reporting and analysis have been undertaken in recognition of the accepted view that ‘Knowledge’, ‘Attitudes’ and ‘Practices’ are interrelated, in that respondents who have a greater Knowledge regarding education of children and youth with disabilities will express Attitudes of concern regarding issues relating to education of children and youth with disabilities and incorporate them within their Practice.

The survey revealed that knowledge regarding education of children and youth with disabilities was extremely limited. This applied to both legislation and provision of relevant services for this group of children. The term ‘disability’ was generally defined by respondents in narrow terms as representing mainly those individuals who have severe physical or sensory impairments, with a consequent tendency to marginalize those who experienced other forms of disability. This has implications for service delivery. Attitudes towards children and youth with disabilities and their families were more positive among younger respondents and more highly educated respondents. The absence of knowledge related to children and youth with disabilities is a significant factor in the responses of the general population, who did not perceive intellectual impairment as a disability. Families of children and youth with disabilities felt that the support that they received both in school and within their community was inadequate. They stated that most of the support came from within their wider family circle and that they felt isolated from other families living with disability.

Among the general population there was a consensus that educational and social provision for children and youth with disabilities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge was improving, and that the support provided by the state was adequate. This is in contrast to families with children and youth with disabilities, who were less positive and felt that they received less support than they required. The data collected indicate that there are a range of enabling factors that provides a platform for potential future developments in support of education of children and youth with disabilities in the Districts of Kamonyi, Bugesera, Kicukiro, Gasabo and Nyarugenge. It is important to recognize that these are at least inferentially associated with the overall national approach to supporting education and social welfare for all children in the country and linked to developments in provision during the last decade or more.

Engagement with schools and teachers during the research process, although not extensive, did suggest that there is some willingness to address issues of educational and social exclusion. There was also some evidence of an awareness of the need to provide disability related professional development for key personnel working with children and youth with disabilities. However, such positive indicators are counterbalanced by omnipresent barriers, which co-incidentally are reflected in many other national settings worldwide. These findings infer synergies between knowledge levels of children and youth with disabilities and resulting positive or negative attitudes towards these children. The connection to formal practices is less obviously demonstrated, given that the case survey did not constitute a prevalence survey. Parental practice, however, was informed by acquired, experiential knowledge of their children with disabilities.

Following data analysis, four target areas have been identified from which recommendations regarding policy, provision and practice for children and youth with disabilities are made. These relate to systems challenges and change, families of children and youth with disabilities, the general population and education professional groups.

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