National Council of Persons with Disabilities

National Commission for Children

REPORT ON NATIONAL ASSESSMENT OF CENTRES CARING FOR CHILDREN WITH

DISABILITIES IN RWANDA

"Every child with mental or physical disabilities shall have the right to special measures of protection in keeping with their physical and moral needs and in conditions, which ensure his dignity, promote self-reliance and active participation in the community."

Article 13, The African Charter on the Rights and Welfare of the Child (ACRWC)

REPORT ON NATIONAL ASSESSMENT OF CENTRES CARING FOR CHILDREN WITH DISABILITIES IN RWANDA

May 2016

CONTENTS

List of Acronyms

ASFA Muganza	Centre des Amies de St. Francois d'Assise Muganza
AR	Annual Report
CWDs	Children with Disabilities
CP	Cerebral Palsy
CWLD/II	Children with Learning Disability/ Intellectual Impairments
DMO	Disability Mainstreaming Officer
DOB	Date of Birth
DPO	Disabled Peoples' Organizations
ECD	Early Childhood Development
EICV	Integrated Household Living Conditions Survey
EMIS	Education Management Information System
ES	Executive Secretary
GOR	Government of Rwanda
HI	Handicap International
HHC	Hope and Homes for Children
HMIS	Health Management Information System
INGO	International Non-Governmental Organization
JADF	Joint Action Development Forum
LNGO	Local Non-Governmental Organization
MDG	Millennium Development Goal
MINALOC	Ministry of Local Government
MINEDUC	Ministry of Education
MYICT	Ministry of Youth and ICT

MIGEPROF	Ministry of Gender and Family Promotion
NCPD	National Council of Persons with Disabilities
NUDOR	National Union of Disabilities' Organizations of Rwanda
N/A	Not applicable
NCC	National Commission for Children
NISR	National Institute of Statitsics Rwanda
PEI	Plan Educatif Individuel / Individual Care Plan
PWD	Persons with Disabilities
REB	Rwanda Education Board
RGB	Rwanda Governance Board
SC UK	save the Children UK
TMM	Tubarere Mu Muryango, National Childcare reform programme
TVET	Technical and vocational education and training
UPHLS	Umbrella of organizations of persons with disabilities in the fight against HIV/AIDS and for Health promotion
VSO	Voluntary Service Overseas
VUP	Vision 2020 Umurenge Programme

EXECUTIVE SUMMARY

The purpose of the assessment was to review service delivery in centres for children with disabilities in Rwanda. The assessment generated evidence essential for advocacy, policy and programme development both for children in institutional care and children with disabilities living in their communities. Data were collected and analyzed for 49 of the 59 institutions listed by NCPD. After analysis, information was grouped in two parts: i) factual data about the institution regarding services offered and funding and ii) an appreciation of how services are provided to children enrolled at each institution. This report establishes relevant baseline information on institutional capacity including services offered, staffing levels and other parameters regarding care of children with disabilities.

In Rwanda, children's rights are aligned to a series of international standards and conventions providing clear guidance to Governments about their responsibilities for all children and specific additional responsibilities and guidance concerning parental and State responsibilities towards children with disabilities. Rwanda has made remarkable progress in aligning national laws to reflect international principles and theoretical frameworks recognizing that disability is a cross cutting issue that should

be mainstreamed across all relevant sectors and Ministries. This is partly achieved through specific services provided to children with disabilities in a number of centres largely run by non-state partners (e.g. Church Based Organizations, NGOs and parent groups). Eighty eight percent of these centres receive funding from the GOR through the NCC and MINEDUC. However, there is need to strengthen this support.

The assessment noted that 15 residential centres, 20 mixed (residential with some day users) and 14 day care centres operate in the country, giving a total of 49 centres. 71% of the centres offer residential care and 29% offer day care services to children with disabilities. 14 of the centres care for children with a single disability; 11 care for those with two types of disability while 24 centres care for those children with more than 3 different types of disability. This may reflect a challenge to accessing services for such a vulnerable population. The number of children at the centres has been increasing since 2013 and currently stands at 4,339. Records showed that there is still a challenge of documentation and 31% of the centres were unable to provide reports on service users for the year 2015. Therefore, the actual number of children with disabilities enrolled may be higher than reported.

On assessment of special education relating to the nature of the disability; Vocational Education and Primary Education, 88% of the centres offer education from pre-school through to vocational education though only half of them use structured syllabus or curriculum to guide education and personal development.

There was a positive correlation between number of staff and number of children where the average number of children per caregiver was 31. Also, 27 of the centres reported that all or most of their staff are trained for the roles they perform. There is need to strengthen inclusion of special education for teachers and health related workers into the Ministry of Education capacity building programmes.

Most children enrolled at the centres were brought by family members, upon noticing that their children were not thriving at the expected rate. A number of children are also referred by local authorities and health centres while a few were abandoned at a centre. This finding provides a basis for the need to strengthen capacity of the family to care for the child at home in appropriate cases.

Eighty-four per cent of centres assess children on admission but only 45% reported developing childcare plans for all children in their care. Only 39% of the centres had records on child development plans that were used for the assessment. However, the quality of the plans was very variable, hence the need for regular tracking in order to strengthen this aspect of care.

Fifty-one per cent of the centres place no limit on the time a child with disability may spend with them while the rest of the centres accommodate young adults alongside younger children reflecting a challenge for children maturing whilst in care and never returning to the family unit. Strategies to increase flow of children through institutions would help to increase effective capacity as places free up.

Parents need to be able to keep the child in the family without compromising the child's development. This review was also done for parents who had been all over the country seeking support. It was revealed that there is an unmet demand for more locally available services which enable parents of children with disabilities to have access to the services without breaking ties between children and their families.

INTRODUCTION

CONTEXT AND BACKGROUND

In Rwanda, care and treatment for children with disabilities started way back in the late 1950s. Church founded institutions such as HVP Gatagara pioneered this kind of program and later grew into a network of service providing centres. By 2016, the range of facilities offering services, care, treatment and support for children with disabilities had become diverse. With services becoming more available and accessible than before, all children are expected to access primary health care and treatment, education, and basic standard of living through core programmes for Education and social protection services. In addition, specialized centres offer specific facilities and services to children with disabilities whose additional and special needs require more focused attention.

Across the country, care centres offer a wide variety of services for children with disabilities such as, special education and basic skills (communication, self-care, mobility) among others. Each institution is in charge of providing oversight to ensure quality care to their enrolled children. As enlisted by the NCPD, there are over 56 centres in Rwanda currently. The centres play an important role in the lives of children with disabilities who access them. This assessment was conducted to provide a better understanding on how these centres function, their capacity, their range of services and how they provide care to children with disabilities with an aim of improving care and service delivery standards.

OBJECTIVE OF THE STUDY

The purpose of the study was to assess centres caring for children with disabilities with regard to their capacity and how they provide care and accommodation for children with disabilities in Rwanda.

Specific Objectives

- Map institutions for children and young adults with disabilities.
- Determine the number of children with disabilities enrolled in the institutions.
- Assess the capacities of institutions for future design of appropriate alternative care.
- Collect and analyze data on practices of care for children with disabilities in institutions, involvement and support from the extended family, society and State.
- Collect and analyze data on accommodation needs of children with disabilities in educational institutions, identify practices of including children with disabilities in the educational process and identify barriers to inclusion.

- Learn more about the rationale for admission of children with disabilities in the respective institutions, analyze the existing procedures for identifying a child's disability, referral pathways for services as appropriate, treatment and follow-up.

PAST STUDIES ON CHILDREN WITH DISABILITIES IN RWANDA

In the past, a few studies were conducted and contributed to knowledge service provision for children with disabilities in Rwanda. The NCPD conducted study visits from March to May 2012 in 44 institutions caring for children with disabilities and provided data from 43 centres giving a total of 2,192 children. This data has been used to determine baseline information against which changes were measured during this assessment.

NUDOR in partnership with MINEDUC, MINALOC, NCC and Handicap International conducted a field visit to some selected centres of children with disabilities across the country to monitor the quality of education offered in the centres. 12 inclusive and special schools were visited but no detailed report on findings is available.

Hope and Homes for Children's study on orphanages (2012) found 144 CWDs among the 3,323 children reported from these institutions. 64 of the 144 were CWLD/II (children with learning disability/ intellectual impairments) or CP (cerebral palsy) and many were not in school due to their condition (the nature of their disability makes integration in the local school impossible). The HHC study highlighted that there are some children with disabilities enrolled in mainstream childcare institutions where it is not always clear that they are benefiting from inclusive services but rather are 'lost in the system without links to family members or care plans specifically tailored to the nature of their disability. In addition, the study found similar examples (of adults aged 40 years who had been cared for by the institution since its inception and others who had been admitted as children and matured into young adults while in care). There are children in care whose family members are unknown based on their history of arrival into care, being abandoned.

In addition, Chance for Childhood also conducted three district level studies to map the number and needs of children (aged 3-25yrs) with disabilities. It was reported that at the request of NCPD, these studies (which were originally conceived to identify children with hearing or speech impairments targeted by an Enabling Education project) be widened in scope and identify the number and needs of all children with disabilities in the country. The reports show that the most common occurring disability is physical impairment with intellectual impairment as the second.

The study also noted that centres which specialized in caring for children with intellectual impairment were the most frequent (14 centres).

METHODOLOGY AND LIMITATIONS OF THE STUDY

Staff from NCPD, NCC and Tubakunde, acted as enumerators after a 2-day training to orient staff on data collection and related tools; 4 teams, each composed of 3 members, visited 56 centres out of the 59 enlisted by NCPD. A standard questionnaire was used to collect quantitative data as well as some qualitative aspects as required through focus group discussions with staff, parents and children in separate groups. Quantitative data were then entered into Excel for analysis and qualitative data were analyzed using Nvivo software. The team crosschecked admission records for the period of 2013-2015; and child care plans for 10 randomly selected children (including 5 males, 5 females) and ranked them using a rapid assessment based on 3 key quality/appropriateness criteria. Information provided in self reports were verified against available documentation in order to show the basic levels of child protection standards. Incomplete data were not analyzed.

LEGAL AND POLICY FRAMEWORK

OBLIGATIONS UNDER GLOBAL AND REGIONAL TREATIES

The rights of children in Rwanda are aligned to a series of international standards and conventions adopted and applied in the country. These provide clear guidance to the Government regarding its responsibility towards children and guidance concerning parental and State responsibilities towards all children with disabilities. The foundation stone of this legal framework is the UN Convention on the Rights of the Child (ratified September 1990).

Rwanda had a turbulent past with war and genocide that led to mass killings, mass population movements and other related challenges. This definitely resulted in enormous barriers to children's' rights such as the right to life, to an identity and everything that follows these basics. Currently, there is a clear set of international and national frameworks in place that have been adopted into laws, policies and strategies to strengthen children's rights in Rwanda, and to bring additional attention to the rights of children with disabilities.

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

Stipulates that,

"in actions concerning the child undertaken by any person or authority the best interests of the child shall be the primary consideration."

Article 13 that addresses specific responsibilities towards children with disabilities states that parties to the Charter will use available resources to progressively achieve full access to movement and to public places (and services) for all mental or physical disabilities.

Every child with mental or physical disabilities shall have the right to special measures of protection in keeping with their physical and moral needs and in conditions, which ensure his dignity, promote self-reliance and active participation in the community.

"Every state shall ensure, that the child has effective access to training, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration, individual development and his cultural and moral development."

Article 13, The African Charter on the Rights and Welfare of the Child (ACRWC)

b) UN Guidelines for the Alternative Care of Children

It is a reality that some children are not able to live in the birth family and in such conditions these guidelines (issued as part of measures to deliver on the CRC) clearly state the principles of care that will be adopted.

Summary:

- It is most desirable for children to live and be raised in the family

- Some families will need State support to be able to do this: to take adequate care of a child with disability; disability costs and care responsibilities are a drain on economic activity

- Where this support is not sufficient, foster family options may be the next best alternative for the child

- If a decision is made that it is in the best interests of the child that they live in alternative care, the organizers should also consider that it is desirable to maintain family links and therefore place the child into alternative care near family members.

The family is the fundamental group of society and the natural environment for growth, wellbeing and protection of children, so efforts should *primarily* be directed to enabling the child to remain in or return to the care of his/her parents, or when appropriate, other close family members. The State should ensure that families have access to forms of support in the caregiving role.

Where the child's own family is unable, even with appropriate support, to provide adequate care for the child, or abandons or relinquishes the child, the State is responsible for protecting the rights of the child and ensuring appropriate alternative care, with or through competent local authorities and duly authorized civil society organizations. It is the role of the State, through its competent authorities, to ensure supervision of the safety, wellbeing and development of any child placed in alternative care and the regular review of the appropriateness of the care arrangement provided.

If decisions concerning alternative care have to be made they should take full account of the desirability, in principle, of maintaining the child as close to his/her habitual place of residence as possible, in order to facilitate contact and potential reintegration with his/her family and to minimize disruption of his/her educational, cultural and social life. Every child and young person should live in a supportive, protective and caring environment that promotes his/her full potential. Children with inadequate or no parental care are at special risk of being denied such a nurturing environment.

These guidelines have clear relevance to the conditions of children with disabilities in alternative residential care in Rwanda and the relationships between Government and its service providing partners.

c) UN Convention on the Rights of Persons with Disabilities and its Optional Protocol

Rwanda ratified the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol on 15th December 2008 without qualification. This means that the Government of Rwanda intends or aspires to address without any exceptions all areas described by the Articles of this Convention, in its efforts to implement the rights of children with disabilities. These articles protect the equal rights of citizens with disability (adults and children) to be registered at birth, have an identity and access to all necessary health, education and child development services. Additionally, the Convention protects the rights of persons with disabilities to have appropriate access to vocational training, skill development and economic opportunity.

Progress in Developing National Legislation & Policies on Alternative Care

There are many examples of the Rwandan law that have been published to reflect international principles adopted. Within National Development frameworks, the national development plan, budget, Sector Ministry Strategies are designed to deliver MDG targets and specific poverty related programmes. There are references to the specific and additional needs of children and children with disabilities and considerable amounts of work by Disabled Peoples' Organizations (DPO) have been done to influence the policy agenda[1]

Since disability is a cross cutting issue; it needs to be tackled from many aspects. The Ministry of Gender and Family Promotion (MIGEPROF) & NCC should be involved since their roles include children. Other stakeholders include Ministries of Health, Education, Justice, Infrastructure and Youth & ICT to mention but a few. The NCPD has been assigned the responsibility of oversight and coordination of these diverse efforts to fully include children with disabilities in the country's development agenda.

The following national laws are in this regard:

a) Law on the Protection of the Child (December 2011)

This describes the ideal norm for raising a child and what should be done in some specific exceptional circumstances.

- *A child has the right to know his/her parents, to stay with them and to be protected by them when they are alive (Article 15).*

- *Where the need for temporary or alternative care arises, a child who is temporarily or definitively deprived of his or her birth family shall be entitled, through the relevant authority, to a replacement protection which could consist of his or her placement in a foster family, an adoptive family or a placement in a relevant social welfare institution. (Article 24)*

- *The Government is responsible for taking care of orphans and other vulnerable children specifically paying the costs of affiliation to "mutual health Insurance" for orphans and other vulnerable children. Local authorities certify the vulnerability of children. An Order of the Minister in charge of children determines modalities for the implementation of this Article (No 41).*

It is also envisaged that some children with a special physical or mental disability shall be placed

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[1] VSO managed National Programme: Realizing the Rights of Disabled People in Rwanda completed May 2009

into a special institution for care and treatment. (Article 42). This may be for a short term or skill specific training/care and indeed this is the role played by several centres currently.

b) The Law[2] relating to the Protection of Persons with disabilities in General

This law is equally clear in its commitment to family life where possible and that where a child/person with disability is benefiting from services in a centre catering for children, these should indeed have a positive role in the child's development process and help the child become more integrated into the family, community and school. Thus, a centre should not substitute for family but provide a positive contribution to overall quality of life. A person with disability has the right to live in the family in the same conditions as others. An orphan with disability who is unable to live on his or her own shall have a tutor or an adopter or a centre or an association that caters for him or her (Article 5). Centres or associations that cater for persons with disabilities are obliged to fulfil the conditions to enable the persons with disabilities to have a decent living in matters relating to security and health. The centres and associations are required to have sufficient capacity and equipment in order to be able to integrate persons with disabilities into social life and to have a role in the development process (Article 4). The State has the obligation to monitor and support the centres that cater for persons with disabilities.

c) MIGEPROF Integrated Child Rights Policy (adopted by Cabinet August 2011)

The policy endorses unequivocally that "Every child matters" and the policy is applicable for all children in Rwanda irrespective of any second criteria (such as disability). All children, aged under 18 years, have their basic rights. Implementation of this policy is expected to strengthen protection and access to these rights.

PROGRESS TOWARD DELIVERY OF EFFECTIVE SERVICES

Any assessment of the effectiveness of services for children with disabilities should consider both the provision that comes through generic, government programming as well as additional and special services provided by other government partners such as care centres reviewed in this study.

Available literature illustrates that the direction of progress in Rwanda is clearly towards a wider understanding of the rights of persons with disabilities including children with disabilities. This is

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2 (No. 01/2007)

highly likely to create greater demand. Application of this policy intent is challenged by resource availability, technical competencies and in some cases, leadership. There are mainstream programmes designed to specifically support the poorest and most vulnerable (such as VUP) yet these do not collect aggregate data on recipients with disabilities and appear to be missing this target for inclusion.

Two strategies are operational in Rwanda; first, the provision of specific services for children with disabilities in separate centres where there is almost no inclusion of children without any disability. Second, inclusive services where a number of children with disabilities are to be fully included in all mainstream services for children and youth (for example secondary and vocational education; health services and youth employment programmes). There is eclectic data about the relative merit of either approach. From the literature review some avenues are suggested for further analysis.

- The EICV4 provides evidence for higher levels of poverty amongst households where the head of household has a disability;
- payment of health insurance fees for CWDs is desirable as a means of ensuring full access to health services for CWDs but this is not fully operational;
- rights and entitlements under current disability law are numerous; many expected to flow from the national exercise in categorization of persons with disabilities (2014/15);
- there is effective tracking of health facility data via HMIS and this system can monitor services used by clients with disabilities or the incidence of new disabilities.
- Some progress has been made with listing a large number of educational units for CWDs and inclusive schools; tracking performance through EMIS now becomes a desirable target.

FINDINGS

OVERVIEW OF CENTRES CARING FOR CWDS IN RWANDA

Out of the 59 Centres that were listed by NCPD, 56 were assessed; 3 centres providing psychotherapy and mental health care facility based services were excluded from the assessment. An additional 7 centres were excluded from the analysis since they did not meet the criteria of being a (residential or Day care) centre catering for children with disabilities. The centres that did not meet the inclusion criteria are shown in Annex 1). Therefore, data were analyzed for 49 out of the 56 centres. The findings are presented as follows:

Basic Database

The list of institutions surveyed was updated accordingly. Data was cleaned to remove institutions or organizations that are not providing services for children with disabilities.

Single focus centres (such as primary or secondary schools) or health facilities were retained but listed distinctly. Centres whose presence on the NCPD database was queried by enumerators after the assessments were flagged red and may need a decision (based on current data) or further investigation.

Figure 1 illustrates the centres by type: 15 residential centres; 20 mixed (residential with some day users) and 14 day care centres. This shows that a total of 35 centres (71%) are able to provide residential care to children with disabilities (this includes 15 centres providing residential and 20 centres providing mixed residential and day care). There are 14 centres (29%) which offer day care to children with disabilities living within reach of the centres.

Figure 1. Basic Categorization of centres for children with disability

Table 1: Number of centres by province and type

|	Eastern	Western	Northern	Southern	Kigali	Total	%
Residential & Mixed	5	8	5	12	5	35	71%
Day	0	4	0	2	8	14	29%
Total	5	12	5	14	13	49	

Number of Centres by Type and Disability Focus

Among the 15 residential centres: 1 is a fully inclusive school. This is a residential boarding school where 84 of 378 students are CWDs. Of the 84, 16 students have hearing impairment while 68 students have physical disabilities. Five centres focus on a single disability, 3 centres exclusively for children with visual impairment; 2 for children with hearing impairments; 2 exclusively for children with intellectual impairments; and 1 small church founded facility that offers accommodation & education to primary school going children with physical disability. The remaining 6 centres offer services to mixed groups of CWDs.

Among mixed residential/day centres there are 6 single disability focus centres: 4 centres exclusively for children with hearing impairments and 2 exclusively for children with intellectual impairments. The remaining 13 centres offer services to mixed groups of CWDs. Among Day Care centres there are 10 single disability focus centres: 2 centres exclusively for children with hearing impairments; 8 exclusively for children with intellectual impairments; also 1 centre caring for children with severe disabilities. The remaining 3 centres offer services to mixed groups of CWDs.

Figure two shows the total number of centres receiving children by type of disability (sample of 36 respondents).

Figure 2: Total number of centres receiving children by type of disability

Number of centres by type of disability of focus
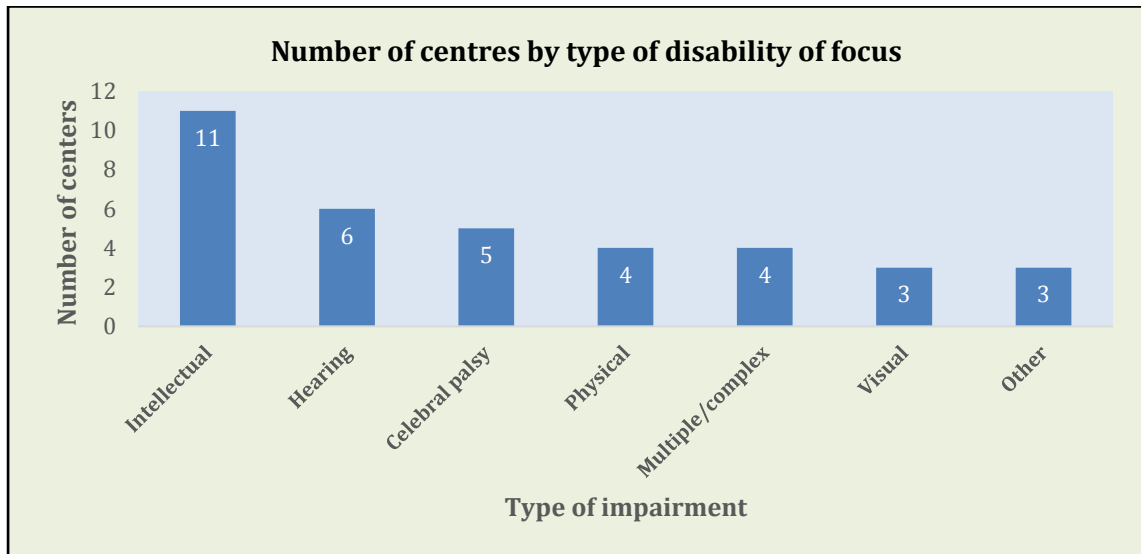
Among the 14 institutions specializing in a single disability: 1 is for children with physical disabilities; 2 for children with visual impairment; 6 for hearing-impaired children and 4 for children with intellectual impairments. The final centre admits only children with complex and multiple disabilities. Among the 11 institutions with children from two types of disability, there is a slight association between some users' conditions. There are 2 centres caring for children with physical and intellectual impairments; 2 caring for children with intellectual impairments and cerebral palsy and 2 where cerebral palsy is associated with another disability.

Figure 3: Number of centres providing services to children with single disability or several impairments
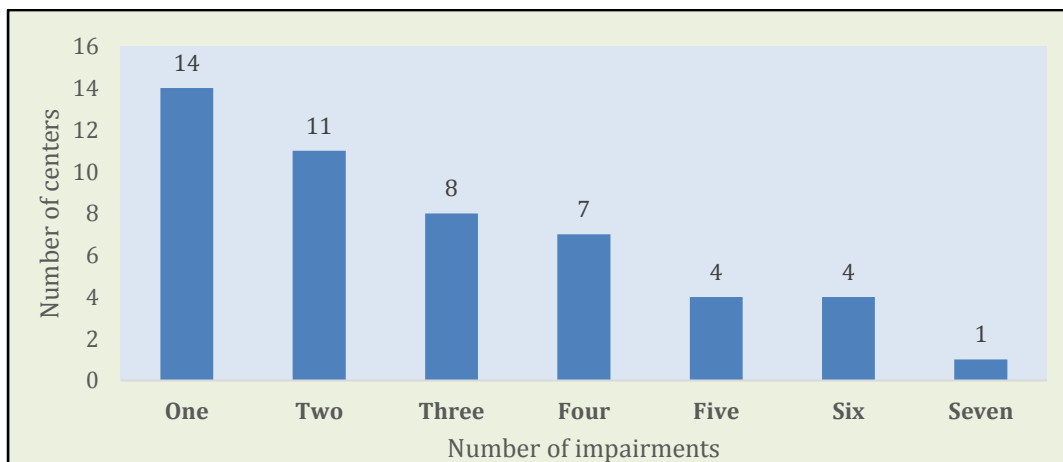
Children, Adolescents and Young Adult Users

In addition to offering services to children, 50% of the institutions do offer services to adults with disabilities. This is a situation that has arisen over time where some centres allow children with disabilities to stay at the centres until they become young adults (from 18 – 25 years).

Other centres are primarily for younger children but have some few students aged over 18 years. This trend appears to reflect a reality that some CWDs have nowhere to go for further, adapted learning or vocational activities and have therefore become institutionalized in the centres as they grow older. Indeed, there was an exceptional centre that had students aged 40 years. In addition, in situations where children have been abandoned at a centre and there are no family links or immediate attempts to trace the birth parents, the children may reach adulthood while still at the centre.

Similar categories of PWDs were identified during the programme to close orphanages and reintegrate all children into families. Admission records show that some children were abandoned at the centres and little was known about their families. This is a potential barrier to the child's family reintegration and development outside or post institution.

Child Care Capacity

Basic record keeping concerning new children admitted, those leaving the centre and the total number of service users (for the period 2103 – 2015) was found incomplete.

- For the year 2013, 39% of the centres were unable to provide figures for the total number of their service users.
- For the year 2014, 43% of the centres were unable to provide figures for the total number of service users
- For the year 2015, 31% of the centres were unable to provide figures for the total number of service users

In many cases where the total number of children was known, the data was not disaggregated by gender and type of disability. Existing figures do show an increase in service utilization over the 3-year period (2013-2015) as shown in figure 3. However, it was not possible to determine the actual number of children with disabilities currently enrolled in the care centres since 31% (15) of the centres didn't provide any data on their service utilization. Therefore, the actual numbers may be higher than those currently reported.

Figure 4: Trends in number of registered users at centres for children with disabilities, 2013 – 2015

Trends in number of registered children at centres for children with disabilities, 2013 – 2015

	1	2	3
Series1	2907	3142	3534
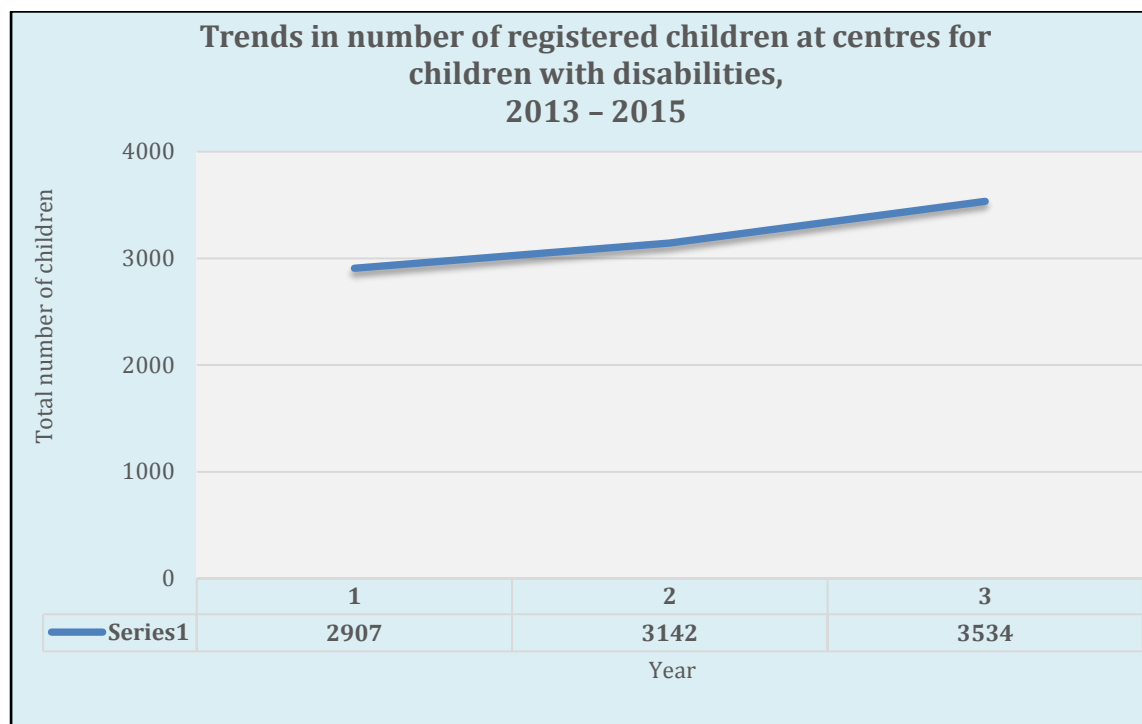
There is an overall increase in demand as shown by the uptake of services at the existing centres. During the 3-year period, only one new centre was created in 2014. However, the centre did not contribute numbers to the reported data since it could not provide records for the period reviewed. Overall, the data is incomplete and gender disaggregates may not be reliably obtained. The reported figure of total number of children using services at the time of this study (March 2016) is 4,349 children.

Testimonies from focus group discussions with parents and children confirmed that there are many other children in homes who need support services yet they are not receiving any support from a particular centre.

This could be a clear indication that demand exceeds supply and as parents share information amongst themselves, awareness on the rights of all children improves in society in general hence triggering an increase in demand for the support services.

Figure 5: Correlation between age of the institution and number of users
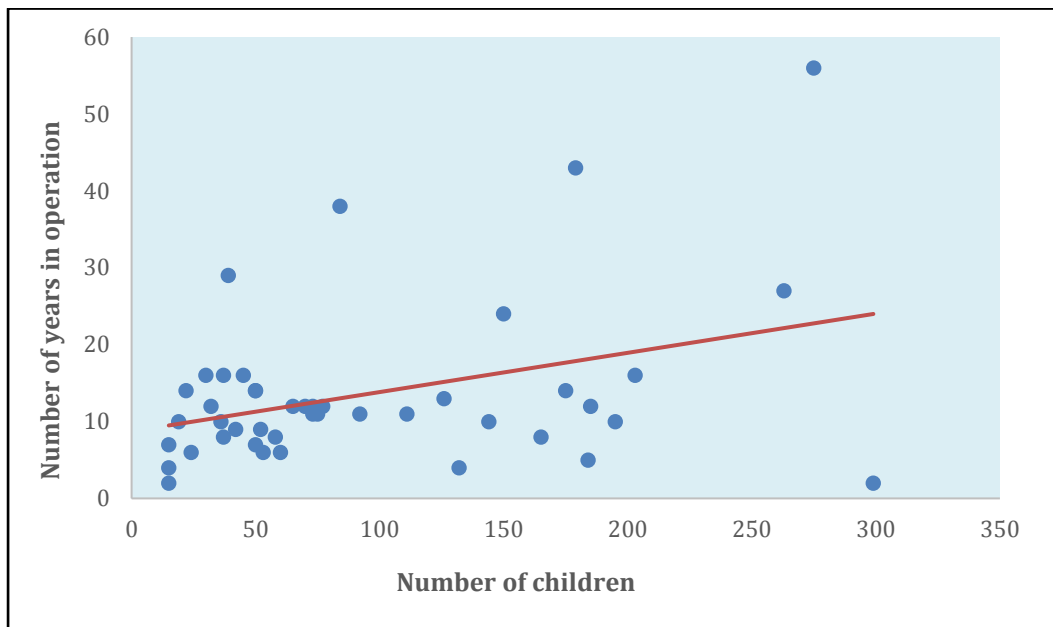
Correlation between years in operation and number of children using the centre = 0.4. This shows that while there is positive correlation (greater than zero) between the number of years of operation and number of children being enrolled in the centres, this is quite weak (less than 0.5). This means that a number of centres have been in operation for many years but are not increasing their enrolment rates. This could be related to the fact that they operate at full capacity and do not have resources to enroll more children. However, there are a few outliers with more children enrolled yet the centres have not spent a long time in operation.

PROFILE OF INSTITUTIONS

Considering the longevity and sustainability of centres alongside their capacity and performance, this study has established the following trend as shown in figure 6.

By Date of Creation

Figure 6: Number of Centres by date of creation
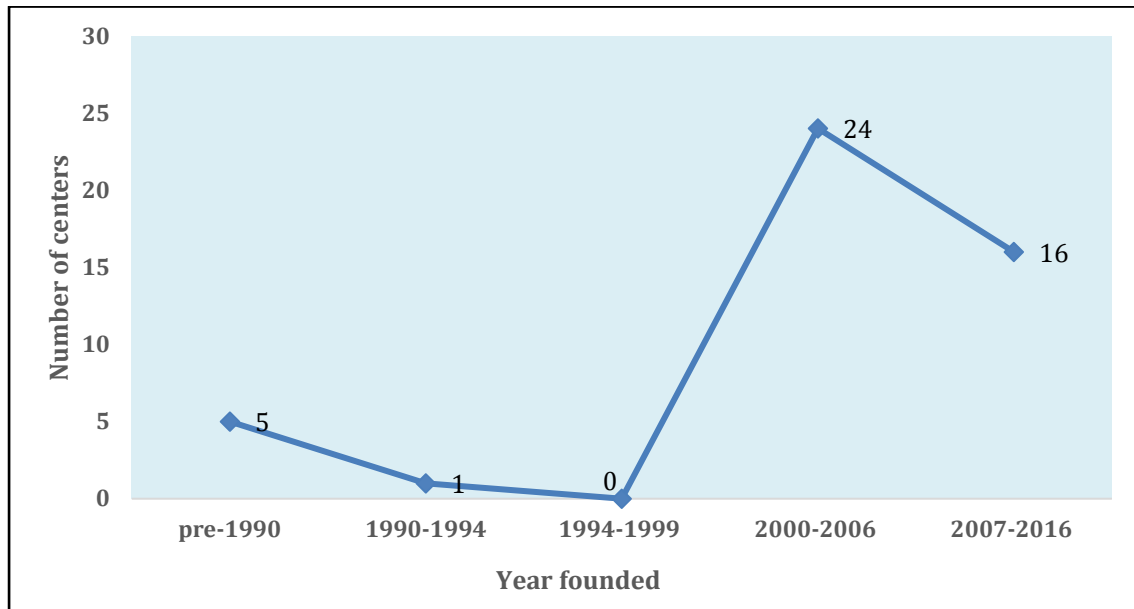
Number of years in operation

The assessment noted that the longest serving care centre for children with disabilities has been operational for 56 years while the newest centres have been operating for the last 2 years.

By Legal Registration and Entity

There are official links and channels for communication and monitoring of the centres' activities. Organizations are registered with the government or other legal entities. The following were the key findings relating to legal registration:

- 88% of institutions (43 centres) reported that they are registered with a recognized government or legal entity; only 6 were not registered.

- 58% of institutions were registered with the RGB. Most of these are also registered with other ministries or districts.

- 54% of institutions were registered with the districts.

- 86% (42 centres) provide annual reports to the local authorities or other authorities such as the district.

- 88% reported that they have received GOR funds within the last 3 years. However, it was unclear whether these funds come with the responsibility to report on their use.

Table 2: Frequency of Registration Points between Institutions and the State

Institution registered with	No. of centres	%
Affiliation to A/Janja	1	2.08
Congregation	1	2.08
District	6	12.5
District & Min Youth	1	2.08
District to MINEDUC & MOH	1	2.08
Eglise Methodiste Libre with RGB	1	2.08
HVP Gatagara Affiliate	1	2.08
MINEDUC	1	2.08
MINEDUC & District	3	6.25
MINEDUC MOH	1	2.08
MINIJUST & RGB	1	2.08
NCC	1	2.08
Official Gazette	1	2.08
RGB	9	18.75
RGB & District	13	27.08
RGB & MIGEPROF	1	2.08
RGB & RUB	1	2.08
RGB, District & MINEDUC	1	2.08
RGB, NCC & District	1	2.08
RGB, REB & District	1	2.08
Unclear	1	2.08
Total	48	100

There was evidence of the centres having linkages with local authorities where some authorities visited the centres. 41 centres had been visited during the previous 3-year period. However, the

visits do not serve as an effective system for monitoring since they are not regular and are conducted independently by various authorities. There might be need for continuous monitoring.

Several centres have not been visited since 2012 or 2013; while others are only visited when there is an official launch/function for which the centre provides an appropriate venue. The following summarizes the various visits recorded:

- Courtesy visits: The President of the Republic of Rwanda, State Minister in the ministry of local government, Honorable Representatives of PDs in Parliament, Ministers of Education and local government.
- Working visits relating to a specific issue: The Police, land officer at sector level, Rwanda Social Security Board representatives and JADF officers.
- Visits from local authorities: Vice Mayor in charge of Social Affairs, Vice Mayor in charge of Economic Affairs, District youth Coordinator, members of District Inspection Committee, District Education Officer, District Disability Mainstreaming Officer, NCPD District Executive Committee, Sector Executive Secretary, Sector Education Officer and Sector Social Welfare Officer.
- There was no evidence to show who from the authorities was in charge of monitoring or supervising the centres to ensure that the centres are providing the required minimum standards of care or are held accountable for use of any GOR funds they receive.

Sustainability of Centres & Sources of Funding

Based on an assumption that operating in buildings owned by the centres provides a level of stability, this study found that 25% of centres (12 centres) operate in rented infrastructure and may therefore be less stable.

Table 3: Ownership of infrastructure:

Indicator	Frequency.	%
Rented Accommodation	12	23
Buildings owned by institution	34	65
Other	6	12

Financial stability may to some extent correlate with diversity of funding sources; and if this is a valid assumption then 38 centres (79%) are more stable having benefitted from 2 or 3 distinct sources of income over the last 3 years (2013-2015).

Table 4: Funding sources

Income	Frequency.	%
Support from a single source	4	8
Support from 2 sources	22	46
Support from 3 sources	16	33
Support from 4 sources	4	8
Support from 5 sources	2	4

One of the most important facts is that 43 centres (88%) report having received funds from the Government of Rwanda during this 3-year period, suggesting that there are channels of Government support to this sector in addition to other incomes. This brings responsibility for reporting and accountability tied to provision of funds although it is not evident that this is being used as a channel for monitoring. Annual financial reports have often been submitted to district authorities. The study made no attempt to quantify annual budgets.

Thirty centres do not receive any funds from external international sources while 18 have received funding in the period under consideration. 25 centres reported receiving contributions from parents although this may also be contribution in kind (labor and participation in care responsibilities). Only 5 centres reported having been able to access any other funds within Rwanda.

RANGE OF SERVICES & INFRASTRUCTURE CAPACITY

What services does this centre/institution offer to CWDs?

The 5 most commonly offered services are presented in table 7 below. This information is however qualified by the quality of some services observed during the research. Centres reported that they offer physiotherapy services yet appeared to be under equipped and poorly staffed in some cases. Statements about level and type of education offered to children were also sometimes qualified by the observed lack of materials, mixed age range classes, and large numbers of learners found in classrooms with just one or two teachers. Nevertheless, this ranking would bring a focus for

strengthening physiotherapy and child development skills; along with primary, special and vocational education expertise.

Table 5: Ranking of Top 6 Services offered to children with disabilities, N=49

Service	Frequency	%
Day care facilities	33	67.4
Residential facilities	34	69.4
Outreach work in communities	20	40.8
Health related services	13	26.5
Physiotherapy / other work to improve mobility	31	63.3
Daily Living Skills (self-care)	30	61.2
Communication skills (Sign language)	14	28.6
Pre-School learning	15	31.3
Primary Education	18	37.5
Secondary education	14	29.2
Special Education relating to CWDs	22	44.9
Vocational Education	21	42.9

What type of education is offered to CWDs?

Forty-three centres assessed (88%) offer education services from pre-school through to vocational level. 41 centres (84%) offer one or more essential services including health related services, physiotherapy, daily living skills or communication skills. 8 centres offer none of these services and only provide education, of which 3 focus on children with hearing impairments, 2 on children with intellectual impairments, and 1 on visually impaired children. The remaining 3 provide a combination of physiotherapy and daily living skills.

…. being in schools with other CWDs has positively impacted their lives, "I don't feel isolated anymore"one of the children said

Table 6: Frequency of Education Options

Education Options	No. of centres offering option
Pre-school only	3
Pre-school and primary	11
Primary only	1
Primary & Secondary	13
Secondary only	1
Special Education only	11
Vocational education only	4
Special and vocational	11
Pre-school, primary and secondary	7
Pre-school, primary, secondary and vocational	5
Primary, secondary and vocational	8

Does teaching / special education follow a curriculum?

Regarding following the education curriculum, 49% of the centres do not while 51% do. However, sources of the curriculum were variable including 11 centres that use a curriculum provided or endorsed by the Rwanda education board (REB) of which 7 work principally with children with hearing impairment, and 1 centre for the visually impaired children. The other 7 centres reported using a curriculum that they developed internally; another 2 with input from a technical partner. 1 centre uses the Belgian Government Special Education curriculum for children with intellectual impairments; 1 centre uses the Kenyan Curriculum for Mental Health; 2 reported use of a curriculum whose source was not cited.

Despite offering education services at some level, only 5 centres are registered with the Ministry of Education. Based on this finding and considering that different centres are using different

curricula, it is important to monitor the quality of education being provided in centres for children with disabilities.

Qualitative Assessment of Infrastructure in Centres

Based on the observed facilities in each of the centres and considering the suitability of classrooms to the type of child being educated; the existence of minimum appropriate learning materials; cleanliness of medical facilities; accessibility for children with

- 19 centres (40%) (albeit subjective) had infrastructure and cleanliness of good quality;
- 16 centres (34%) with poor quality and condition of facilities and need immediate attention;
- 12 centres (26%) with facilities that are of an adequate standard although there is room for improvement.

physical disability or visual impairment where these attend the centre; the number of staff trained in sign communication for centres receiving children with hearing impairment; separate accommodation and latrines for boys and girls and overall impressions of the centre, an assessment of quality of infrastructure can be made as shown in the box above. Among residential centres, 7 scored well overall. 6 centres are in poor quality and require immediate attention. Among day care centres, 3 scored well overall and 6 centres are in poor state and require immediate attention. Some centres appear to be non-functional and also indicate other causes for concern such as having children with hearing impairment but not having any staff member trained in sign language communication. Against the specific criterion of single sex accommodation, only one centre offering residential care did not meet the standard. In 7 of the 35 centres offering residential accommodation, latrines were not separate. This situation was also noted in 5 of 14 day care centres.

HUMAN RESOURCE CAPACITY & QUALITY OF APPROPRIATE CARE

Do the institutions have sufficient and trained staff to care for the children in their centre?

The correlation between total staff and total number of children using services was 0.65. This means that there is a reasonably strong link between the 2 variables and indicates that institutions/centres with more children tend to have more staff. This observation does not apply to some few outlier centres where there are large numbers of children and few staff. This is illustrated in the scatterplot below.

For the scatterplot below, the number of children is taken from the 2016 reported actual total number of children currently using the services of the institution (both non-resident and resident users)[3] and the number of paid staff is the reported number among the people who work to deliver services and are paid. [4]

Figure 7: Numbers of children using centre services compared to numbers of paid staff providing these services
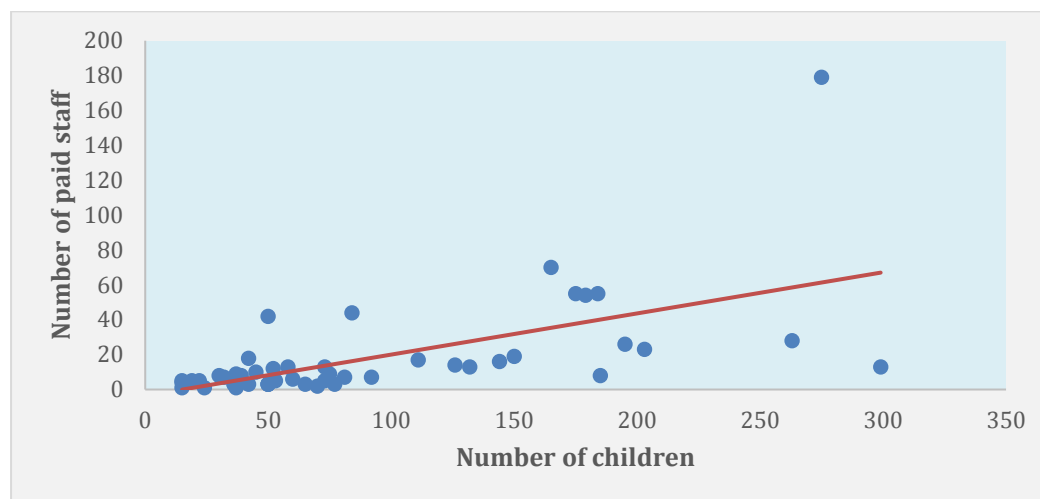
Table 7: Staff to children ratios:

Variable	Average	Standard Deviation	Minimum	Maximum
Ratio of paid staff to total number of children	10.37	8.6	1.19	37
Ratio of children to caregivers	31.2	23.8	5.25	97.5

The average ratio of children using the services to caregivers would be higher considering that caregivers actually work in shifts since they cannot all be working at once (which is the assumption behind the average).

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3 A5 Total in Data Set

4 As opposed to unpaid volunteers or family members; data taken from B10_1 in set

Are centres able to recruit technical staff that are already trained or do they mostly have to train them in service?

Table 8: Trained staff

	Frequency.	%
Recruited with training/experience	32	68
Trained in service	18	38

The majority of the centres assessed (68%) reported recruiting already trained or experienced staff instead of having to train them in service. 18 centres reported that they are able to recruit staff and then train them in service although they require a minimum skill levels and competencies before recruitment.

Proportion of staff in technical roles who are formally trained to undertake this work

Eleven centres reported that all their staff in technical roles are formally trained while 16 centres reported that most of their staff in technical roles are trained. 6 centres reported that only some staff are trained.

Figure 8: Proportion of Centres with formally trained staff

PROPORTION OF CENTRES WITH FORMALLY TRAINED STAFF
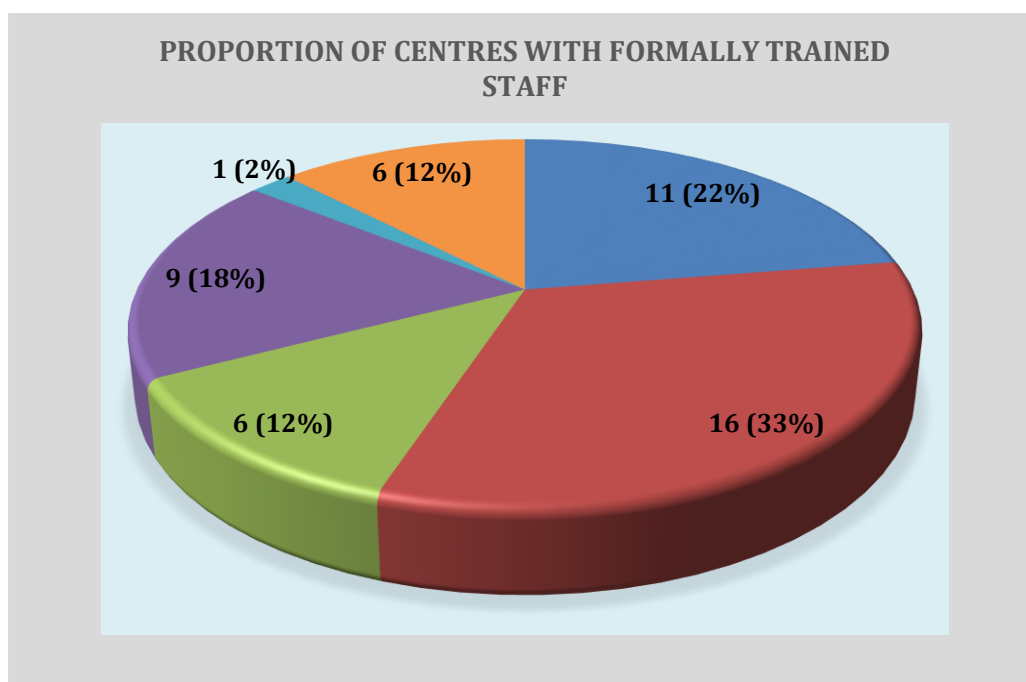
The centres reported that they received more technical training to strengthen staff skills with support from NGOs or other non-Government programmes other than through mainstream government programmes. 15 of the 47 centres with education programs reported that they had received support in form of technical training from the government while the majority (74%) received the training from NGOs and other programs.

CHILD CARE SYSTEMS

How well are the particular development needs of CWDs met by the systems of the institution in which they stay?

Although there was a good percentage of positive responses to the question regarding keeping basic data on children in care, there was no sound evidence for self-reporting.

Findings are as follows:

Table 9: Screening of children at time of arrival

Response	Frequency	Percent
No	6	12.2
Yes	41	83.7
N/A	2	4.1
Total	49	100

Table 10: Medical assessment or assessment of functional capacity

Response	Frequency	Percent
No	7	14.3
Yes	42	85.7
Total	49	100

Table 11: Individual care plan for children

Response	Frequency	Percent
All	14	28.6
Most	8	16.3
None	12	24.5
Some	9	18.4
n/a	6	12.2
Total	49	100

Twenty-eight per cent (14) of the centres had an individual care plan for all children in their care, 16.3% and 18.4% had a care plan for most and some of the children respectively while 24.5% had no care plan at all.

Admission procedures

Review of childcare plans by type of centre for 10 randomly selected children:

Among Residential Centres:

- 6 centres had no care plans
- 4 centres had records of how children arrived at the centre and their disability type but no care plan
- 4 centres had care plans for all the 10 children randomly sampled

Among Residential / Day Centres:

- 8 centres had no care plans
- 3 centres had records of how children arrived at the centre and their disability type but no care plan
- 8 centres had care plans for all the 10 children randomly sampled

Among Day Centres:

- 6 centres had no care plans
- 2 centres had records of how children arrived at the centre and their disability type but no care plan
- 3 centres had incomplete records only

- 3 centres had care plans for most of the children randomly sampled

The reasons for this attribution is not clear.

> - It was suggested that sometimes a care plan is a prerequisite for child sponsorship; this may explain why some centres do not develop care plans for all children and only develop for some.
> - In some centres care plans were all made on a particular date, written in English only and appeared to coincide with the presence of international technical experts who could have helped with documentation. Children arriving at the same centres after this date were not assessed.
> - In other cases, focus group discussions with parents and staff illustrated that the normal academic process of reporting on performance in school was taken as the sole indicator of child performance. Whilst this is one proxy indicator of progress, a school report does not equate to a child's development plan and progress milestones for a wider skill set of mobility, communication, socialization, self-care and self-confidence.

The data above also negates answers given to questions relating to regular assessments of each child's progress and keeping individual records to substantiate this. There is some amount of false positive reporting in this area, hence the need for developmental care for each individual child.

REINTEGRATION – EXIT PLANS, CHILDREN'S FUTURE

Duration of stay in centres

25 of 49 centres (51%) reported that there was no limit on the time a child may spend in the centre. This flexibility or lack of exit plans brings with it the risk of having some children institutionalized. This was evidenced by the high proportion of centres (49%) with adults in their care. Where residential centres limit the duration of stay;

> - 5 centres use an age milestone (up to 18 years, 22 years or 25 years of age);
> - 7 centres set the duration of stay (though this is highly variable ranging from 3 months to 5 years depending on the services offered);
> - 3 centres use an education milestone to limit attendance with children leaving once they have attained P6 or Senior 3 / 9 years' basic education;
> - 6 centres use a capacity milestone where children leave the centre when a certain level of progress has been achieved.

For day care centres there is less risk that family relationships will be severed and the child becomes institutionalized. Nevertheless,

- 6 centres (43% of day care centres) set no limit on the time a child may attend;

- 3 centres reported that children leave the centre according to progress made;

- 1 centre (offering TVET) limits attendance to 6 months;

- 4 centres use an age milestone to trigger exit (this varies from 12 years, 18 years or 25 years of age).

A number of reasons are given for children leaving a centre. The most common reason is that the child is moving to another suitable centre (29/48 responses); the second common reason was death of the child (23/48 responses); and the third was that in case the child's family does not see any added value in having their child attend the centre (19/48 responses). Among Day care centres it is also common for children to stop attending the centre if the family relocates to another area.

What mechanisms are there to maintain contact between children in care and their families?

Are there mechanisms in place to encourage continued contact between child and birth family- How often does this system described above happen?

Table 12: Contact with families

Response	Frequency	Percent
Frequently	16	32.7
Occasionally	14	28.6
Rarely	4	8.2
n/a	15	30.6
Total	49	100

Among the residential centres only 1 centre reported that all children in their care are orphans and no attempt is made to maintain any contact with their birth family members.

All other residential centres reported that parents are actively encouraged to visit their children whilst they are at the centre. In 3 centres it was specifically stated that children return home during holidays. There are attempts made to maintain contact between centre and family whilst a child is at home

- 6 centres rely on calling parents or parents calling them if they have a concern;

- 6 centres reported that they make home visits;

- 1 centre reported that they collaborate with community health workers although it is not known how this relationship was established;

- 1 centre stated candidly that they have no means of knowing.

Evidently because of distance, there is less contact with families of children in residential centres. Only 2 residential centres (13%) reported making any attempt to assess the quality of home-based care and hygiene; this is considered as a proxy indicator of concern about the 'whole package of care' for the child with disability – an awareness that home-based care can be as important as the centre based services to a child's development and family life.

Table 13: Assessment of knowledge of parents/family members on basic hygiene and social care for their children

Response	Frequency	Percent
No	11	22.5
Yes	30	61.2
N/A	8	16.3
Total	49	100

Table 14: Support for better levels of care in the home

Response	Frequency	Percent
No	13	26.5
Yes	28	57.1
N/A	8	16.3
Total	49	100

Twenty centres (41%) across the whole sample reported doing outreach work in communities. This proportion did not significantly change amongst day care centres only, where 6 centres (43% of subset) reported doing outreach work in communities although this might be easily managed by a day care facility where there is regular interaction with families.

Referral Mechanisms

Analysis of data from child records, where these were made available, shows that amongst the 186 children whose referral pathway to the centre was recorded:

- 159 (85%) were brought by a parent or other carer;
- 4 (2%) presented at centres having been advised by a DPO (Persons with disabilities Organization) or a District DMO (Disability Mainstreaming Officer) to contact the centre;
- 20 children (11%) were referred by another institution such as a health centre, school, and the police;
- 2 children (1%) were left at the centre by an unidentified person.

Thus, in the majority of cases, family members are known and family links can be established and sustained with less effort. Only a very small number of children are abandoned and would need additional effort to provide alternative family care with a foster family.

SPECIAL NEEDS AND CHILD PROTECTION MEASURES

Specialized care

36 centres out of 49 that responded (75%) reported that they aim to specialize in the care of specific disabilities; although 24 centres (49%) reported receiving children with three or more disability types. While centres may aim at becoming specialists in a particular type of disability and care, the reality is that almost half of them end up receiving children with many different disabilities due to high demand and diversity of disabilities. This is a challenge to providing appropriate care and development support across a range of disabilities.

Individual Record keeping

Forty-three centres out of 49 that responded kept individual child records but only 19 could provide some form of individual development records. Many of these were more than 2 years old and scored zero against this criterion.

Only 24 centres (50%) record accidents or any specific issues arising (such as those pertaining treatment and care in the centre or during home stays). This does not represent a basic standard of protection for children in care. There are also specific challenges for these children with disabilities in care; some are not able to express themselves well and must rely on the attentiveness of staff or empathy of those caring for them to notice if they are unwell, unhappy or ill-treated. Non-verbal signs such as loss of weight or aggressive behavior may reasonably be taken as a proxy indicator for a particular child having a problem. In cases like these, it raises concern that misbehavior is often reported as a reason for children who leave the centre.

Additional and Special Needs

This study found 38 centres (78%) reporting that all or some children in their care require treatment for epilepsy and 22 centres (45%) needed additional support to avail ARV treatment to some of their children who live with HIV. The study was unable to explore whether all children are routinely informed of their HIV status or not and to determine if there exist any systems in place for confidentiality.

Sexual and Disability Based Violence

Violence against CWDs in the community is a reality evidenced by referrals to the centres by the police. Children who have reported rape are sometimes referred to the centres as a safe haven. This was confirmed through testimonies with parents who said they brought their children to the centres for safety after they had experienced sexual or disability based violence in the community. One of the centres also reported that the users of their services had on a number of occasions

been subject to sexual violence when moving between their homes and the day centre. In addition, during a focus group discussion, one of the children reported family abuse.

There was no evidence that sexual abuse occurs when children are in residential care although some indicators and risk factors were observed during the assessment. Among children in the care centres some cases of pregnancy were observed. The study team did not explore the circumstances of the pregnancies. It was noted however, that some centres accommodate adolescents and minors. Night time supervisions of single sex dormitories may not be sufficient to remove any such risk considering the high numbers of children per care staff on duty.

Just as some members of society mistakenly equate disability with inability; some parts of society do not fully recognize that young adults with disabilities may be sexually active no matter their disability, including those with intellectual disability. In one of the centres, it was reported that young boys choose to leave the centre seeking to be independently sexually active when they feel mature enough.

This study confirms that children with disabilities are not free from sexual abuse and suggests that further community sensitization would be essential. It would also be good to work with Isange One Stop Centres and the police to curb the vice. Relevant persons taking decisions about care for a child with disability should not automatically consign children with disabilities to residential accommodation but rather work to make the home and community environment safer for all children, especially vulnerable children.

ADDITIONAL QUALITATIVE FINDINGS & STAKEHOLDER VIEWS FROM FGD

Access to Quality Care

Several centres for children with disabilities are located in remote places that are hard to reach. Distribution of centres is uneven; by specialism and by location; not every District has a centre (e.g. Kirehe).

Resources are often limited and even within centres specifically for CWDs, access in the face of uneven terrain, older buildings and few facilities remains a challenge. This could probably limit the quality of care although parents, during group discussions, showed enthusiasm in providing good quality for their children.

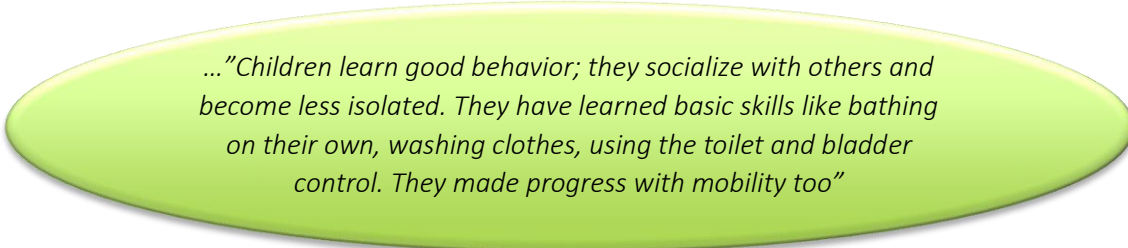### Awareness of Centres and Arrival pathways

Most parents with CWDs found out about existence of these centres by word of mouth. Some had struggled and moved up and down to find help but had poor information and there were no clear sign posts from local authorities.

There were examples of centres that conduct community outreaches to proactively identify CWDs during discussions. Some parents have come from as far as DRC, Burundi and Tanzania to bring children with disabilities for treatment in Rwanda. Referrals from within the country are from health facilities, churches and the police.

Churches were mentioned positively in terms of respect for CWDs. Among local authorities and some communities, attitudes to CWDs are still biased (negative) or negligent (neutral but with the result that CWDs are ignored). Both parents and children mentioned a large volume of unmet needs in their home areas.

Key Achievements for Children in the Centres

Parents reported positive changes in their children in many aspects. They were able to quantify this on a scale of 1 to 10 and to give supporting details as to why they felt the centre was useful for their children.

…*"Children learn good behavior; they socialize with others and become less isolated. They have learned basic skills like bathing on their own, washing clothes, using the toilet and bladder control. They made progress with mobility too"*

Parents' perception about their children with disabilities has changed. They recognize that children need protection and have rights (to education and healthcare). Stigma is decreasing although still present; children's progress helps the family and immediate neighbors to look at the child more positively. It was also noted that having a safe centre looking after the child during the day frees up the principal carer for other family and economic activities.

Children in centres value social interaction with other children in similar situations. Some wished that school holidays were shorter and noted that *'our teachers are helping us much more (than our families were able to do)'*. Many groups want to have more opportunity and equipment for sports and leisure activities, as well as equipment for learning or vocational activities.

Several groups of children were concerned about their future. Given that they have been taught productive skills, they will need support with materials to form producer groups. For those who

seek employment not entrepreneurship, advocacy for young adults with disabilities seeking to enter the labor market is vital.

Child Progression and Time spent in Centres

It was very common to find centres with no limit on the duration of stay of CWDs in the centres and expectations that some children may stay forever because their disability is either permanent or there are no family links. Consequently, some children are institutionalized and never return home. Children in primary education may repeat classes several times and normal progression is not always achieved. However, parents and staff all recognize the potential for individual children to develop.

"Yes there is a change, even remarkable change, in our children," some parents said.

Family contact varies but it is highly important in achieving positive change. A child's ability to progress is often linked to the parents' attitude to their children and taking up responsibility for their CWDs. Parents who are engaged and active reported that they had witnessed changes in their children which reduced some care burdens and promoted self-esteem of their children.

Some day care centres require a family member to remain with the child at the centre and this comes with a cost for the rest of the family. Some staff expressed low expectations about children exiting the centre, and exit strategies were not very tangible even though these were described in theory. TVET is seen as a long-term strategy and desirable pathway since children with disabilities grow older and may not be able to progress in formal education. However, there should be caution in automatically advancing some children with disabilities to vocational skills with no basis in formal communication, numeracy and literacy. Vocational skills should therefore be an additional option not a substitute for some level of basic education.

Children and parents value the services the centres provide and could be more involved especially in discussions with specialists to understand care options for their children. Children's development was often diagnosed by medical /technical experts without sufficient reference to parents' inputs regarding their children's behavior, moods and expectations. A comparative analysis of key themes from 9 focus groups using Nvivo software showed the following as important themes in the discussions:

- Training

- Family Contact

- Follow up

- Educational progression

- Lack of access to facilities, services or equipment

Parents noted that the centres had positively impacted the lives of their children. Although still present, the issue of stigma has reportedly reduced; parents' perception about children with disabilities has also changed and now, many recognize that their children need protection and have rights (to education and healthcare) like everyone else.

12 year old Ugirinshuti Janviere makes an illustration during an event organised by NISR and UNICEF. The event was dubbed, "Reading Data with Children."

CONCLUSION

The study reviewed 49 centres caring for children and young adults with disabilities. The centres are run by a range of non-state sector partners, churches and parent associations and have some level of funding from the GOR especially through the NCC and Ministry of Education. It was noted that there is no formal monitoring system in place. Almost half of the centres accommodate the children, some are day care centres while others provide accommodation and day care services.

Although the records were incomplete at many of the centres, it was evident that the number of children using the services has been increasing since 2013. Most of the children are brought to the centres by their parents or other family members. Local authorities and health centres also refer some children while others are abandoned at the centres, although these few. The main source of information about the centres is provided through word of mouth by fellow parents who have children with disabilities as well as church campaigns.

Many centres operate at full capacity and are unable to enroll other children with disabilities who are in need of services, indicating that demand is still high. The quality of services is variable, with some centres providing very high quality services while others provide very low quality services. Centres providing good quality services could serve as examples for the low performing centres to learn. However, this requires a regulatory or monitoring system to ensure that services meet the desired standards. Quality could also be affected by the inadequate number of staff working at the centres.

Given the funding challenges for existing centres, alternative models should be scaled up including mainstreaming of more children with disabilities into core services. For example, as ECD centres are created in greater numbers (as part of core Education Strategy and as part of VUP /Public works support programmes), collaboration should be encouraged between relevant stakeholders (NCPD, NCC, Districts, existing centres and potential users). Since a number of centres were using various approaches and curricula for their teaching services, it would also be important that the relevant regulatory authority further analyses the situation to ascertain the level and quality of education being provided in the centres.

EMERGING ISSUES

STRATEGIC DIRECTIONS & SHARED RESPONSIBILITIES FOR INCLUDING CWDS/PWDS

Delivering on the ambitions of international and national legal frameworks requires inter-ministerial collaboration and budgeting within sector plans for the full inclusion of all children with disabilities. It was not clear whether there exists a strong technical lead in mainstreaming strategy.

- For example, the Ministerial Order prescribing that the Health insurance costs for orphans and vulnerable children (including CWDs) be met by the State needs full resourcing;
- Until every child with a disability has received some level of basic education and skills development appropriate to their abilities, Rwanda still has a way to go as far as free primary education and 9 years' basic education for all children is concerned.

Committing Government resources to scale up was a specific request from parents of children attending schools for the deaf who felt it was desirable that their children progress into inclusive education, but this needs more sign language training and resources for teachers / learning support assistants. The request is generally valid although important amounts of international funding are directed towards the disability sector.

SCALING UP PROVISION IN SUSTAINABLE WAYS

Centres for children with disabilities have increased in number and have increased the number of children in their care but they do not seem able to accommodate all of them as needed. They provide an essential complement to mainstream services but are clearly stretched to meet the level of demand and quality of services. Parents recognize the value of the support they and their children receive but call for increased access for many others in their home communities who do not have access to any support services yet.

Creative ways of scaling up appropriate, sustainable models such as small community "homes" near schools, foster care during term time for some, increasing community outreach and community based or home based care should be further explored. As social protection schemes are implemented on an increasing scale across Rwanda, more effort should be made to ensure that these provide the support necessary for families affected by disability to bear the additional

costs associated with this and still retain the child in the family where this is practical and the best option for the child.

Scale up should aim to fully include all CWDs. The mechanism to provide free health insurance to vulnerable children once fully costed and operational should assist families with CWDs to ensure that they access appropriate health care.

It may be possible to draw added value from GOR investment in developing a qualified social work workforce (already made as part of TMM programme) by using this cadre to support families having children with disabilities more effectively, and generally to provide better community level support to children with disabilities who have no access to centre based services. There has been considerable effort in increasing access to education for children with disabilities. Tried and tested approaches (for example the Inclusive Futures work successfully piloted and evaluated by VSO/HI) should be scaled up to address nationwide demand for quality inclusive education. Since early childhood education units are already established, these could also serve as where interactions could support early detection of childhood disability or developmental delays.

Technical oversight by relevant technical or regulatory authorities is irregular and could be strengthened by building understanding of disability among all other relevant levels of decentralized local authorities. A comprehensive programme of capacity development should be explored for technical staff and supervisory bodies be identified.

RECOMMENDATIONS

Demand and supply

- Funding relationships and working/monitoring communications should be strengthened to improve the link between Government and centres.
- Focus on Social Protection frameworks, benefits and subsidized services for children with disabilities so that mainstream programmes are supporting children to remain in their families with adequate care.
- Other mainstream services such as Health, Education, and Youth Employment & ICT should also be supported to meaningfully include children and young adults with disabilities in all services.

Quality of care

- Standards Operating Procedures should be established and all centres should be required to adhere to the standards. These might for example include holding up to date basic registration and family data; child identity; annual updates on review of progress; basic level of education standards including teacher competencies and curriculum use among others.

- There should be a comprehensive capacity building programme to address the need for further training for technical and care staff at the centres. This should also build knowledge and capacity to plan adequate services amongst district officials and others with oversight of the centres and services they offer.

- Community Alternatives to residential care and services should be explored; using the new network of social workers created under TMM, families with children with disabilities should be reunified and long term plans for children in care developed. A system of progression is desirable with children spending an appropriate length of time attending a centre and moving back into family life.

- Families should be supported to provide extra adequate care for any child with disabilities; stakeholders should work to ensure that existing measures to support poorer families are inclusive for children with disabilities and their families; meanwhile disability grants or child grants should be accessible.

Other Arising Issues to be addressed immediately

- There is need to maintain an accurate NCPD database.

- Collaboration of the Ministry of Health and communities would be helpful to prevent occurance of CP and Epilepsy that results from prolonged labour.

- Need to address the issue of children born in care centres by mothers with disabilities.

- Explore issues related to the lack of identity for many CWDs in care; family obligations upon death of child in care; and the legal identity of orphans in the Centres.

- Engage Sector and District authorities on the issue of violence against children with disabilities. Recall on risks and responsibilities.

- The ratio staff/child should be given particular attention to ensure that CWDs are given optimal care as they are in centres.

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ANNEXES

Annex One: Summary Information on Centres excluded from Analysis of Sample

Name of Centre	Field of Intervention	Founded	CWDs Nos.	Reason for exclusion from Sample
Nyange Primary School	Mainstream Primary School	1997	8 boys 1 girl	Received 9 CWDs since 2009 when Centre du Jour Nyange was closed and CWDs transferred
Amizero Group Burera	Community based group of young PWD /CWDs	12/2012	93	Church initiative linked to Diocese; supports schooling, medical needs and IGA; not a service providing centre
Urugo Rw'Amahoro Mutenderi	Care of Adults with Disabilities	05/2005	11	Activity of Kibungo Diocese; 1 girl of 16yrs others all adults with disabilities abandoned by families
Association Agahozo	Foyer Social: provides support to CWDs in families	Not known	104	Byumba Diocese initiative; administered by one Sister (Nun), no staff; funds for school fees and medical costs from NCC funds and Liliane Foundation: *merits further investigation; impact unclear*
Medical Facilities:				
Physical Therapy Centre Gahini	Short term physiotherapy treatment delivered by Department. of Gahini Hospital	1982	27	Short term physical therapy for CW physical disabilities referred within healthcare system and accompanied by a parent

Child's Orthopedic Surgery Centre Rilima	Pediatric surgery referral centre; formerly orphanage	1999	Capacity 70 beds	Medical facility providing short term care, surgery and post-op physiotherapy. Results monitored by MOH within HMIS
RBC Inkuru Nziza	Orthopedic Hospital	03/1997	4 at time of survey	Medical facility; Integrated within MOH systems; Kicukiro District Office

Annex Two: Assessment of Institutions providing Care and Accommodation to CWDs

Methodology Matrix (v. Inception Report 14032016)

Information Criteria/ Programme TORs	Programme evaluation Narrative/elements	Sources of verification used	Methodology	Process/tools/Outputs
Basic Listing of 57 Institutions	Type of institution (state; private etc.) Capacity Services Physical Address Contact details	NCPD data NUDOR data Monitoring data from responsible Ministries (Education; Vocational training; health services)	Desk review and comparison of lists to be provided	Output: Mapped distribution of Institutions Analysis of spectrum of institutions by type and scale

Application of International Standards	To what extent is Rwanda addressing international standards adopted	UNCRPD & Rwanda Report July 2014 And other national reports (e.g. Rwanda progress on application of the CRC)	Screening for specific provisions for CWDs; cross check for resource budgeting where possible Understanding of challenges / successes in adopting international guidance to date Deepened with appreciative enquiry key informants during fieldwork	Desk review Listing of key relevant issues Output: Priorities for children in Institutional care are understood
Application of National Standards	Legal and policy frameworks put in place to govern this What level of quality control exists	Investigation of application of TMM programme Reporting within MOE on learning progress of students with disabilities in institutions	Consideration of Protection issues for children in care reaching the justice system	Understanding which Government bodies monitor policy application and its outcomes for CWDs
Profile of institutions: legal stature, reporting and monitoring	Mapping of range of institutions; formal, parent-led, church run	District level reporting/monitoring if applicable; Reporting to DEO on	Internal reports	Output: understanding the spectrum of institutional care available and how effectively this is monitored

	and the oversight for each category	learning progress of students in institutions	Data prepopulates *questionnaire based institutional assessment*	
Infrastructure capacity	Listing of key infrastructures and services (education, health related, latrines & accommodation)	Visits to conduct Mapping of range of institutions' services and assets	Questionnaire Observations	Understanding the spectrum of institutional care available and some of the challenges faced
HR Capacity; other resources and quality of appropriate care	Review internal capacity for care across staff team	Voluntary disclosure of internal management arrangements by institution to the Assessment Team	Survey based data collection in all 57 institutions; *Staff Assessment Form* Followed by Key informant interviews in sample	Appreciation of staff resources and technical capacity to provide care to a recognized standard
Child care capacity: assessment, care plans, family links, protection systems	Consider how well the particular development needs of CWDs are met by the systems of the	Admissions procedures Child care plans	*Child Data Collection Form:* Detailed review of child care plans and development pathways from admission to	Understanding of systems used to deliver standard of child care and personal development

	institution in which they stay		date of review, for a targeted sample of CWDs	
Reintegration – exit plans, children's futures	What functional mechanisms are there to maintain family contact and provide for progression for the CWDs or reintegration into family life	Child care plans Reintegration plans for children returning to home based care or progressing to another institution	Survey based data collection in all 57 institutions Followed by Key informant interviews in sample	Analysis of interfaces between institutions and communities
Special needs: HIV, epilepsy, mental health treatments	Are systems for treating additional and special needs of some CWDs in place and functional	Special Child Protection policies and their application: e.g. accident books, confidential records, medical records, child files	Survey based data collection in all 57 institutions Followed by Key informant interviews in sample	Special Child Protection measures that are in place (or lacking) are understood

Annex three: Data Sources

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

Annex Four: Qualitative NVivo output for comparisons

Word data on discussions in 9 focus groups was treated using this software and data from all other focus groups was submitted in handwritten scripts so processed manually using the principles of Nvivo. The following issues emerge as key topics.

- Training
- Family Contact
- Follow ups
- Educational progression
- Lack of access to facilities, services or equipment

This is shown in the table below, '*sources*' refers to the number of centres where a sub-theme was referenced and '*references*' refers to the number of times the sub-themes was referenced across the centres. For example, this tells us that not only did several groups talk about the issue of educational progression, but that they mentioned it many times. Other arising issues are as listed.

Name	Sources	References
Activities	0	0
Career kick start	2	2
Follow ups	1	1
Outreach	3	3
Training	8	13
Benefits	0	0
Awareness raising	6	7
Child satisfaction	4	4
Educational progression	6	11
Family contact	9	15
Follow ups	6	6
Health care	2	2
Life skills training	5	9
Non-selective admission	2	2
Parent satisfaction	1	2
Progression to career	2	2
Staff retention	5	5
Teacher satisfaction	2	2
Deficits	0	0
Barriers to educational progression	4	6
Familial marginalization & stigma from society	2	2
Family non-contact	2	2
Inexperienced staff	1	1
Lack of access to facilities, services, or equipment	7	15
Lack of clarity about next steps	1	1
Limited follow up	2	2
Unbounded length of stay	2	2
Varied age groups at entry	1	1