

**HOPE
AND
HOMES
FOR
CHILDREN**



**THE CLOSURE OF AN
INSTITUTION FOR
CHILDREN AND ADULTS
WITH DISABILITIES**

GOOD PRACTICE GUIDE

June 2021



TABLE OF CONTENTS

1. ACRONYMS	iii
2. EXECUTIVE SUMMARY	4
1. INTRODUCTION AND CONTEXTUAL BACKGROUND	5
1.1. JUSTIFICATION	5
1.2. SCOPE	6
2. KEY CONCEPTS	7
2.1 INSTITUTION CARE	7
2.2. DE-INSTITUTIONALIZATION (DI).....	7
3. DE-INSTITUTIONALIZATION PROCESS	7
3.2 STEP 1 - ENGAGEMENT	7
3.2 STEP 2 - ASSESSMENT	10
3.3. STEP 3- SERVICE DESIGN AND PLANNING	17
3.4. STEP 4- TRANSITION	19
3.5. STEP 5 - MONITORING AND EVALUATION	26
5. CASE MANAGEMENT	28
6. TOOLS USED FOR DI OF CHILDREN WITH DISABILITIES	29
7. SOME SUCCESS STORIES	29
8. LESSONS LEARNED FROM THE TRANSFORMATION OF CIZ AND WM INSTITUTIONS	35
9. FACTORS WHICH CAN CONDUCT TO PLACEMENT BREAKDOWN	36
10. STAKEHOLDERS' PERCEPTION ON THE REINTEGRATION OF CHILDREN WITH DISABILITIES IN FAMILY –BASED CARE	37
11. SUSTAINABILITY: PERCEPTION OF HHC INTERVENTION	37
12. CHALLENGES	38
13. EFFECTS OF COVID-19 ON THE REINTEGRATION PROCESS	39
A. COPING MECHANISMS TO FACE CHALLENGES RELATED TO THE COVID-19	39
14. REFERENCES	40
15. APPENDICES	42

ACRONYMS

CIZ	<i>Centre Inshuti Zacu</i>
CM	<i>Case Management</i>
DI	<i>De-Institutionalization</i>
ECD	<i>Early Childhood Development</i>
ES	<i>Executive Secretary</i>
GOR	<i>Government of Rwanda</i>
HVP	<i>Home de la Vierge des Pauvres</i>
HHC	<i>Hope and Homes for Children</i>
IZU	<i>Inshuti z'Umuryango /Friends of Family</i>
KII	<i>Key Informants Interviews</i>
MIGEPROF	<i>The Ministry of Gender and Family Promotion</i>
MINALOC	<i>The Ministry of Local Govrnment</i>
MM	<i>Malayika Murinzi</i>
MOU	<i>Memorandum of Understanding</i>
NCC	<i>National Commission of Children</i>
NCDA	<i>National Child Development Agency</i>
NCPD	<i>The National Council of Persons with Disabilities</i>
No	<i>Number</i>
NUDOR	<i>The National Union of Disabilities' Organisations of Rwanda</i>
RWF	<i>Rwandan Franc</i>
TMM	<i>Tubarerere Mu Muryango</i>
TOR	<i>Terms of Reference</i>
UNICEF	<i>United Nations International Children's Emergency Fund</i>
WM	<i>Wikwiheba Mwana</i>

EXECUTIVE SUMMARY

Hope and Homes for Children and its stakeholders documented the process of de-institutionalization (DI) of children with disabilities specifically the good practice in the closure of institutions. The exercise was conducted for the two pilot centres, Wikwiheba Mwana and Inshuti Zacu, located in Gatsibo and Kicukiro districts respectively.

This document outlines 5 key steps that serve as an effective blueprint for a successful reintegration process of children and disabilities. These include 'engagement', 'Assessment', 'Design & Development', 'Transition', and 'Monitoring & Evaluation'. The engagement step is a continuum that seeks to clarify the circumstances leading to children's separation from their families, attitudes of families towards institutional care, overall practices and attitudes towards institutional care among institution owners. It allows to inform stakeholders the importance of family based care and seek their participation in De-Institutionalization.

Secondly, the assessment step aims to map existing resources and establish support needed for future placement of children with disabilities. Assessments also enable identification of needs and support for case management and service delivery. Thirdly, the design and development step entails selection of cost-effective alternatives for successful reintegration of children with disabilities into families while ensuring support provided aligns to circumstances and needs of the families. Fourthly, the transition step ensures that children with disabilities and families including foster families are prepared adequately for family-based care.

It is important that all stakeholders are actively contributing to the transition process. Lastly, monitoring and evaluation plays a crucial role in ensuring quality assurance of the interventions provided specifically whether there is impact being

realised by the primary beneficiary i.e. children with disabilities

Interactions with different stakeholders shows evidence of positive impact among children with disabilities as a result of institution closure. Children with disabilities have continued to experience tremendous improvement in terms of wellbeing, healthy family relations, improved health conditions, and linkage to community resources among others. Despite expressed fears, the reintegration of children with disabilities into family-based care is possible when all steps of the DI have been adhered to. Furthermore, for sustainability to be guaranteed, it is important to engage all stakeholders at all stages of the DI process.

A lot remains to be done to address identified systemic gaps and challenges in the DI process, including inaccurate background information on children with disabilities, inadequate services at health facilities and schools, poor mindset and low engagement by institutions, communities and families, among others.

A number of recommendations have been highlighted to facilitate the improvement of reintegration of children with disabilities into family-based care. Some of these include monitoring and evaluating all reintegrated cases before nationwide scale up; strengthening family ties with all family members before the placement of children with disabilities; creating strong networks around children with disabilities including parents/ caregiver, local leaders, and frontline volunteers (IZU) to strengthen linkages; addressing concerns of stakeholders (other than resistance) regarding DI; ensuring that Community Based Health Insurance (Mutuelle de Santé) covers all disability related ailments; and design and operationalize a comprehensive database for all children with disabilities in institutions and the community.

1. INTRODUCTION AND CONTEXTUAL BACKGROUND

Hope and Homes for Children works in partnership with the Government of Rwanda and other partners to strengthen child protection systems and childcare reforms in Rwanda. Since 2000, it has pioneered and demonstrated a range of successful family strengthening models and gatekeeping mechanisms in Rwanda.

In 2012, the Government of Rwanda developed and approved the National Strategy for Child Care Reforms. Learnings from the successful Mpire PEFA pilot institution closure, findings of a national survey of institutions for children, jointly conducted by the Ministry of Gender and Family Promotion and Hope and Homes for Children and a recommendation from 7th children summit, greatly influenced the National Strategy for Child Care reforms. In 2016, the National Commission for Children (in 2020 merged with the National Early Childhood Development Program (NECDP) to the National Child Development Agency-NCDA) confirmed that 3335 (88,1%) children and young adults out of 3782, have been placed into families and other alternative care arrangements. The remaining children are in 4 institutions.

While the first phase of National strategy for childcare reform targeted institutions known as orphanages, foundations of the second phase targeting centers for children with disabilities are in place to ensure no child is left behind confined in Institutions. Findings of the National Survey of Residential Institutions for Children with Disabilities in Rwanda estimated that 2040 children with disabilities were in 34 institutions¹. The successful professional pilot closure of a centre for children with disabilities in Gatsibo District in the rural Eastern Province of Rwanda and a promising ongoing pilot closure of the second institution in Kicukiro District in the City of Kigali, is to inform the national

disability inclusive De-institutionalization Programmes. Current documentation is drawn from case management processes applied during the above mentioned pilot projects.

The de-institutionalization process was made possible due to close collaboration between stakeholders including Gatsibo and Kicukiro Districts, the management of Wikwiheba Mwana and Centre Inshuti Zacu, NCPD and NCD Agency under financial support from UKAid.

1.1 JUSTIFICATION

According to Human Rights Watch² “In many countries, children with disabilities are often deprived of their liberty, separated from family environments, and confined to institutions or locked away in so-called health-care facilities in the name of care and treatment. The reasons for this isolation vary: stigma, lack of awareness and a dearth of support services for children and their families all play a role.”

Documenting the process of de-institutionalisation (DI) and outcomes for children with disabilities aims to demonstrate how DI is possible and how imperative it is for children with disabilities to live within a loving family environment and in safe communities. It also aim to emphasise the potential for inclusive family-based alternatives care in an African context, while ensuring no child is left confined to harmful institutions.

In Rwanda, the Government developed a striving program of care reform and family strengthening called Tubarerere Mu Muryango (TMM), translated to *Let's Raise Children in Families*³, to enable the closure of institutions and promote family-based care. With Hope and Homes for Children and UNICEF support, the program has

1. Hope and Homes for Children (2021), National Survey of Residential Institutions for Children with Disabilities in Rwanda

2. <https://www.hrw.org/news/2017/03/07/children-disabilities-deprivation-liberty-name-care-and-treatment>

3. <https://bettercarenetwork.org/library/social-welfare-systems/child-care-and-protection-system-reforms/tubarerere-mu-muryango-tmm-documentation-of-child-care-reform-program-in-rwanda> (2019)

seen over 3,000 children reunited with families and communities since 2012. Rooted in Rwandan cultural values, the program places strong emphasis on family care while building strong, sustainable child protection and care systems in Rwanda. TMM is an ongoing transition of child protection and care systems that are based on family and community action.

Hope and Homes for Children has been piloting the closure and transformation of the first two institutions for children with disabilities since 2018 in both urban and rural settings with focus on a demonstration model, which includes the placement of children into family-based care and the development of community strengthening services.

This document is to collect all the learning and considerations from the pilot stage for future projects. It is to provide guidance to other partners committed to implement

disability inclusive DI project in Rwanda and beyond.

1.2 SCOPE

This guide covers key elements of the pilot closure including process, challenges, success and recommendations as reference of how to reform an institution for children with disabilities. This model serves to inform the operationalization of DI at national and regional levels.

It is important to note that even though the target institutions are for children with disabilities, the reality is that there are also adults with disabilities living in these institutions. This is a situation that has arisen over time where children stayed longer in centres due to lack of any exit plans. Therefore, this documentation concerns children and adults with disabilities from Wikwiheba Mwana and Centre Inshuti Zacu institutions.

2. KEY CONCEPTS

2.1. INSTITUTION CARE

The definition given by Transform Alliance Africa (TAA) of an institution reflects perfectly our own understanding of an institution:

An institution is any residential setting where children and young people are subjected to an “institutional culture”, often characterised by features such as depersonalisation, rigidity of routine, lack of individual support or personal treatment. Care lacks consistency, permanency and continuity. In this set-up, children experience exclusion; segregation from the wider community social-cultural life, often with a lack of contact with birth families or care givers. The term covers a range of facilities, which in different contexts may be called ‘institutions’, ‘orphanages’, ‘child care centres’, ‘baby homes’ or ‘children’s homes’, ‘children’s villages’, ‘rescue centres’ etc. Some

institutions may be run by the state, others by private providers, some may be materially well resourced, while others may struggle to provide basic amenities.

2.2. DE-INSTITUTIONALIZATION (DI)

De- Institutionalization⁴ of children is a policy-driven process of reforming a country’s alternative care system, which primarily aims at decreasing reliance on institutional and residential care with a complementary increase in the family and community-based care and services; preventing separation of children from their parents by providing adequate support to children, families and communities; and preparing the process of leaving care, ensuring social inclusion for care leavers and a smooth transition towards independent living.

4. https://www.openingdoors.eu/wp-content/uploads/2014/11/DI_Lessons_Learned_web_use.pdf

3. DE-INSTITUTIONALIZATION PROCESS

Regardless of the rural or urban settings, in the process of finding a family for every child residing in the two institutions and ensuring safety and sustainability of the placement, the following steps proved to be instrumental:

- I. Engagement,
- II. Assessment,
- III. Service Design & Development,
- IV. Transition and
- V. Monitoring & Evaluation.

strong opposition due to the long term reliance on institutional care for children with disabilities.

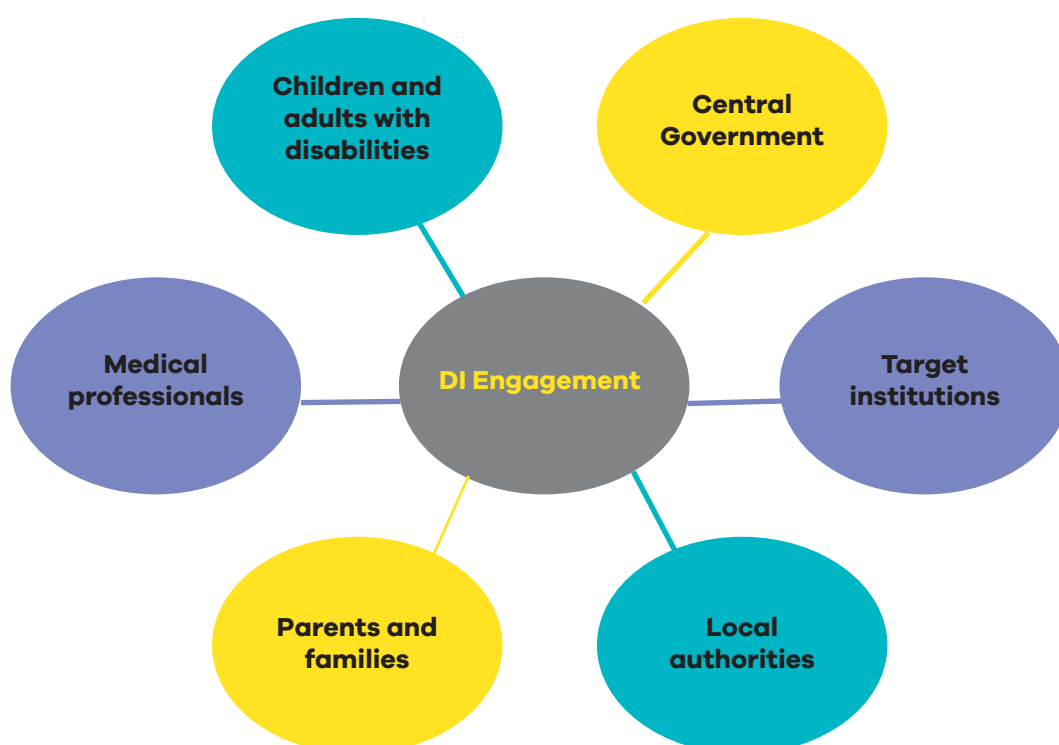
Because of the sensitivity to DI, particularly DI for children with disabilities, it was crucial to secure ownership and leadership of the government. The commitment of the Government of Rwanda to ensure every child is raised in a family gradually increased collaboration of institution managers.

3.1 STEP I - ENGAGEMENT

Institutions' negative effects on children, families and communities have been documented by many researchers, showing that institutional care hinders emotional, physical, cognitive and psychosocial development during childhood as well as outcomes in adult life. But in practice, when we started engagement with different stakeholders we were surprised by the

A tripartite MOU was signed between Hope Homes for Children, NCPD and the former NCC (now NCD Agency - National Child Development Agency) defining roles and responsibilities of each party towards the successful implementation of the pilot closures. Further partnerships were secured, as well, with districts authorities and institutions as a result of continuous engagement.

Case Example. Stakeholders to engage in the DI process



Key stakeholders engaged include government at the central level, local leaders where the institution is based, and families to receive the children and adults with disabilities into their care. Engagement also concerned managers and staff, donors or partners of the institutions.

The main challenge encountered was that during the first contact, the majority of the children and adults with disabilities, and their families, raised many concerns on whether the process will benefited them or not. Some stakeholders at different levels showed reluctance towards the principles and modalities of the DI process. The main reasons for resistance to DI included, but not limited to, inadequate information on the process and its benefits to children and adults with disabilities, fears at family level, hidden intentions for maintaining institutions, uncertainty of livelihood/employment by institutional owners/staff, reputational dilemma of institution (affected status of heroism), and modalities of transition (immediate vs gradual support).

Therefore, engagement is a continuum that needs to be reinforced in order to realize stakeholder acceptance based on the universal human rights and child rights approach. The role of organizational management is to provide consistent support to the case managers, to ensure choices/decisions are made appropriately while mitigating fears and delays to place children in the right families, within their communities. It is also important to continue ensuring that supervision to case managers is regularly conducted. Engagement comprises accountability at the community level, thus, the involvement of the religious leaders, local leadership in the DI process is required.

Engagement was done in different ways depending on the target groups:

- Individual meetings
- Ordinary meetings
- Group sessions
- Workshops
- Counselling sessions
- Play groups

- Child participation sessions

Examples of guiding questions used to facilitate the above ways of engagement:

- Why are children with disabilities in institution?
- Why are they not with their parents?
- How do they feel about not being with their family?
- Why do they not return home?
- What do institutions do for them?
- How do parents feel about their children being in the institution?
- What do parents think institutional care does to children with disabilities?
- Does the community have anything in place to help parents and children with disabilities?
- What happens that makes parents send their children with disabilities away to institutions?
- Can the community do something about it?
- Can parents and the community do it differently?
- What does government think about institutional care?
- What does institutional care bring to government?
- Can government do something about broken children, families and communities?

The dialogue helped to see their understanding, evaluate their perceptions and readiness towards DI for children with disabilities. This helped to be proactive and focus on the benefits of raising children with disabilities in family and community care rather than being blinded by barriers.

Engagement is a continuous process throughout DI, to work on circumstances of separation and parent's attitudes towards institutional care, evaluate service provision at community level & triggers leading to children's institutionalization, and overall attitudes and practices regarding separation and use of institutional care. Engagement is a long and continuous process till the last child is transitioned out of the institutions and even after placement.

• Financial Engagement by HHC

Although project resourcing is done in a timely manner, projections are complex and difficult to forecast as DI is expensive with all the frequent emergent needs, such as health care with specialists, basic comfort in the family like the need for assistive devices such as wheelchairs, sometimes the relocation of an entire family in relation to the community and existing services like schools, hospitals etc. The projection and identification of needs for reintegration will continue to reflect the existing community standards of living and provide appropriate support for child placement into families. Learning from the experience of closing the first pilot residential centre, Wikwiheba Mwana (WM), will inform the closure of the second pilot Centre Inshuti Zacu.

3.2 STEP 2 - ASSESSMENT

Assessment is an important aspect of the de-institutionalization process for children with disabilities. Assessments need to be done with key stakeholders for a successful implementation of the DI process including institutions and their environment (staff and communities), children in the institutions, parents, relatives and foster care families, and available resources where children will be reintegrated.

The objective of an assessment is to:

- Map out support required to transition out of institutional care – children and parents
- Map out support to develop/ strengthen adequate community responses & gatekeeping
- Identify additional support required by professionals to ensure case management
- Identify requirements to develop new services and capacity to deliver end users.

A number of assessments were conducted:

- Institutional assessment
- Initial child assessment
- Family assessment
- Community assessment

Institutional assessment: this included collecting, analysing and reporting data from institution records and information provided by the institution management. This provided a general picture around the background, the routine, characteristics of facilities, staffing, donors, funding, services, residents (children, young adults, disabilities, education, reasons for placement, area of origin, who placed them), etc

Initial child assessment included detailed individual information on each child.

Case Example. Key findings from the institutional assessment of Centre Wikwiheba Mwana

<p>The current total number of residents was 26 (male 11, female 15). Since 2007, the institution welcomed 80 residents and 54 were reintegrated into their families until 2016</p>	<p>11 of 26 were adults aged 18 and above, the dominant age range was 12-17</p>	<p>All 26 children/ adults supported by Wikwiheba Mwana had disability. 65% suffer from mental and physical disability</p>
<p>WIKWHEBA MWANA was established in April 2007 by 9 Parents among them 4 had children with disability.</p>	<p>Wikwiheba Mwana had 4 donors like: NCC, INGEAR Organisation, Association Flammando-Rwandaise and individual donors</p>	<p>The institution employed 17 staff including 7 caregivers who played the role of Mother of the children</p>
<p>Among 26, only 4 residents attended inclusive schools outside the institution (3 in primary and 1 in secondary school), 13 attended school within the institution, while 9 children were unable to attend any school due to their level of disability.</p>	<p>Children were coming from 6 Districts in Rwanda with a majority from two neighbouring districts – Nyagatare District with 12 and Gashyamba where the institution is located with 8. Wikwiheba Mwana institution is closely located to Nyagatare District.</p> <p>This indicated that there was a 'pull' effect of the institution on the surrounding community, whereby the institution was perceived as an easy and effective solution for child care</p>	
<p>The institution had 46 CWDs. After a visit by members of parliament together with State Minister of Ministry of Local Government they recommended the institution manager to reintegrate all children who have families, which led to spontaneous reintegration of 20 children with their families.</p>	<p>The annual budget was estimated to 16,000,000 Frws</p>	<p>The institution employed 17 staffs: 1 coordinator, 1 technician, 2 security guard, 1 cook, 1 pupils guard, 1 cleaner, 1 shepherd, 7 caregivers, 1 physiotherapist, and 1 teacher</p>
<p>26 children catered for by 7 caregivers, The caregiver/ child ratio of 1/4</p>		

Center Inshuti Zacu was initiated on 14 May 2000 by a Catholic congregation of religious sisters named "Inshuti z'abakene" – "Friends of the Poor".	All the residents in Center Inshuti Zacu are Persons with disabilities. 32 of them are both with mental and physical disabilities. 3 have only mental disabilities, 4 of them have physical disability only. 1 young adult has a mild intellectual delay.	40% (16) of residents come from Kicukiro District where the institution is located.
The total number of residents was 40 by September 2018. They were 17 males and 23 females. Since the beginning of the institution up to that time, 49 residents were admitted, 4 of them passed away and 5 of them were reintegrated by the institution manager.	52,5% of residents were aged above 18, another 47,5% were children under 18 years old. The dominant age range was 2-10 with the percentage of 37,5% . The youngest was 2, the oldest was 35.	
The institution employs 25 staffs, 9 of them are religious sisters, 5 livestock workers, 1 physiotherapist, 1 teacher, 2 cooks, 3 security guards, 3 canteen workers and a gardener.	Only 20% (8) residents were in contact with their families.	The congregation Inshuti z' abakene of religious sisters has full power for all management decisions and a strong influence to residents, and staff of the institution.
Children were catered for by 5 religious sisters during the day, making the caregiver / child ratio = 1/8. 3 religious sisters take care of residents at night, making the caregiver/ child ratio = 1/13	Out of 40 children in the institution only 12.5% children attended formal education. 30% had access to special education provided in the institution. Another 57.5% didn't access education at all.	Out of 40 residents, 26 received regular physiotherapy services.
4 children were reintegrated in their families since the beginning of the institution, these children had families and the sisters decided to reintegrate them because no special services were provided to them in the institution.	In the first years of the institution, there was an informal way of accepting residents to come with no recommendation from Local au-thorities. But later, new entrance could come with a recommendation from Local authorities.	Center Inshuti Zacu had a partnership with Center icyizere from Ndera Hospital which visited monthly to provide medicines for residents with mental illness.
		The source of budget was from NUDOR, NCC, Individuals, farming, livestock, canteen activities of the institution.

A standard tool was filled in by the case manager. This tool facilitates the collection of the following data on each child: demographic data, age, sex, information on parents/ family, area of origin, contact with family and relatives, reason of placement, people who brought the child in the institution, education, behaviour, health conditions, recommended placement, etc.

The assessment was done through reading the records, interview with the child/ staff, direct observation of the child, plays, drawings, etc.

This assessment is complemented by a psychological assessment using a tool with respect of the age of the child and health conditions (disability). Portage tool was

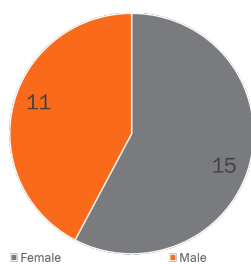
used for children between 0-6; Social and Personal Development Scale (SPDS) tools for typical and children with disabilities with the age above 6 years old. Portage and SPDS were designed with respect to the age range and health conditions.

In addition to mentioned actions; a crucial step of medical assessment done by specialized medical team was completed for all children with disabilities who were residents in Wikwiheba Mwana and Centre Inshuti Zacu.

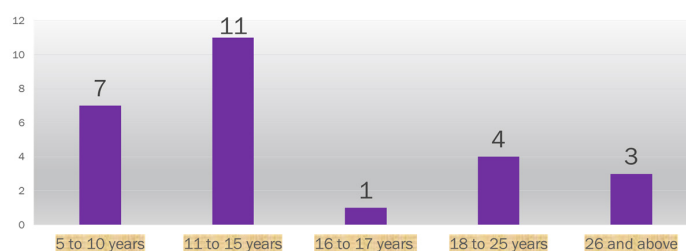
The initial child assessment completion is followed by the development and implementation of the individual care plan based on child's assessment result.

Case example 4: Some of Initial child's assessment results:

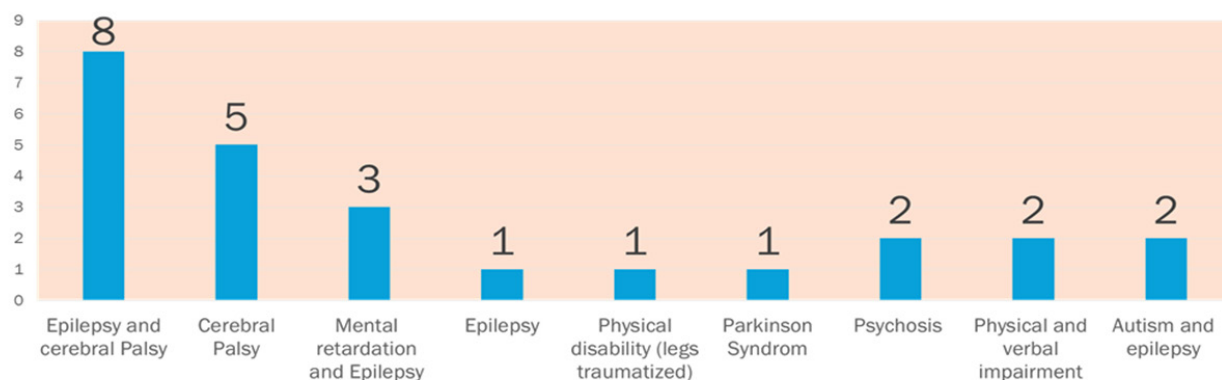
Gender of residents



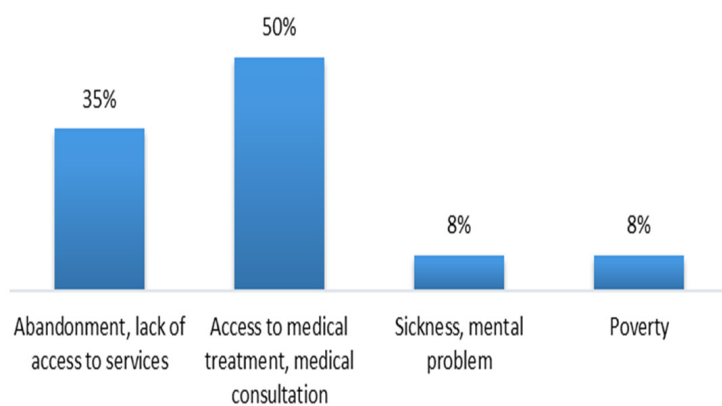
Age range of residents



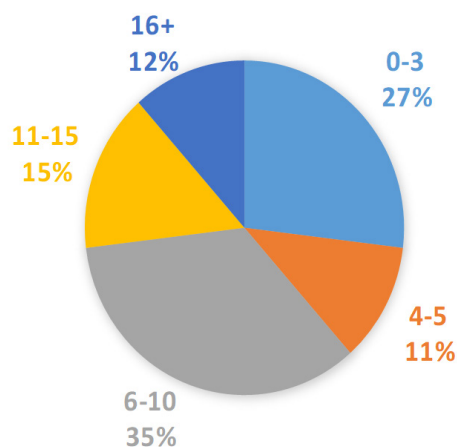
Disability type of residents based on medical diagnosis



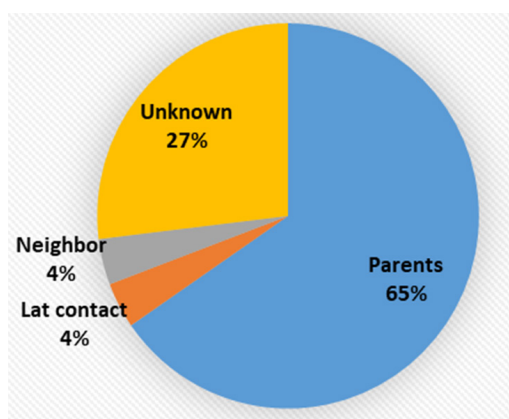
Reason for admission into the institution



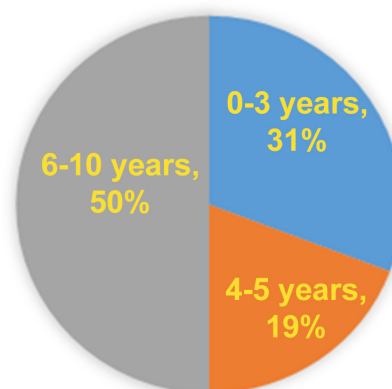
Age at admission into the institution



People who brought children and young adults to the institution



Time spent in the institution



Children support and the community preparation/ Wikwiheba Mwana

10 groups of PWDs from 14 families of CWDs placed in family-based care were provided with psycho-social support and introduced them IGA Groups or Cooperatives to insure the community inclusiveness of PWDs at Community level.

7 out of 26 CWDs have been provided to get wheelchairs, 2 commode chairs, and Working frames.
5 CWDs have been helped to get medical support from GAHINI and RIRIMA Hospitals (Intensive physiotherapy sessions), One CWD was supported to get surgery at King Faisal Hospital. 15 CWDs were supported to get medication from District Hospital, Health centre, and NDERA Hospital.
All these activities were performed to ensure CWDs placed in family based care are having adequate health support and good physical and mental health in their respective family

A peer support group was created in the sector of NGARAMA, to support 6 families of CWDs reintegrated in family based care, and 35 families of CWDs in the Community.

2 schools were supported to get proper toilets for CWDs.

A young adult with disability was supported to get a sewing machine.
2 CWDs were supported to get laptop machines due to their limited mobility of hand muscles.
All these activities were done to ensure children with disabilities are being supported to have access to Education.

All 26 families were linked to the bodies working at the community level, IZU, NCPD Coordinators, Community health workers to ensure the community monitoring of the CWDs placed in family based care.

Children support and the community preparation/ Centre Inshuti Zacu

All 16 children placed from CIZ got basic materials: Sleeping arrangement (bed, mattress, bed sheets and bed covers), clothes, shoes and suitcases, 3 young adults placed in independent living receive monthly support.

All 16 children were supported to build a relationship with family members, extended family members and community members.

16 children were linked to health institutions and some of them are receiving regular health services according to their needs. They were also linked to available community-based mechanism from village to district level, IZU, NCPD Coordinators, Community health workers, DMO to ensure their community monitoring.

All 39 children received individualized care plan implementation, individual sessions, and group sessions according to their capacity.

18 children out of 40 who lived in CIZ received health support through medical check-up at CAREAS NDERA Hospital for mental status examination done by experts (neuropsychiatrist, psychiatrist, and mental health doctors) in order to assess children's abilities and limitation. This check-up involved the presence of parents for preparing them to receive the children and recognize their capacities. 14 children received medical check-up from RIRIMA Hospital, 5 of them were operated and provided orthopaedic devices like special wheelchairs and corsets, 2 children received intensive physiotherapy and one of them received orthosis and 1 child received a tripod can, 6 children were checked in different other hospitals like KMH, CHUK, MASAKA Hospital. Note that five placed children receive regular medical support, and one young adult receives medical support for his mother who has mental problems.

4 out of 16 placed children were admitted in inclusive education and they received educational support (school fees and school materials), as well as 1 child received scholarship from HHC to INES Ruhengeri University with all education cost.

1 young adult was supported to run Income generating activities

8 out of 16 children received special support: 3 received special toilets according to their disability, 3 children were provided commode chairs and other 2 children received diapers.

All 16 children received care plans, 5 of them received special detailed design of care plan implementation according to their disability and their parents received training accordingly.

6 children were registered in civil status registration.

1 young adult received a house (purchased by HHC)

3.3. STEP 3 - SERVICE DESIGN AND PLANNING

Service design and planning: this is the use of all the data collected from the completion of initial child assessment. With the analysis, the data collected informed the development of appropriate services for transitioning children and the type of services that are needed for prevention. With this activity, the real picture of the institution was known and the planning of consequent activities became relevant. The tentative placement options were designed such as the number of children to be reintegrated with their biological parents, children to be placed into extended families, guardianship/ adoption, adults to start independent living, and available post placement support/resources.

The planning component included the relevant services that need to be used, strengthened or established in the community to sustain the placement or prevent family breakdown. The hot spot zones were identified and the appropriate services (training of community health workers, establishment and training of CDNs members, day care centre, saving groups, nutrition and play groups, etc.) were established with regard to the information collected through the initial assessment.

Case Example: Service development in Gatsibo district while closing Centre Wikwiheba Mwana (WM)

During the implementation of the project, different services were created in the community where Wikwiheba Mwana Centre is located i.e. reinforcement of CDNs with focus on children with disabilities, special foster care within all sectors of the district, creation of parent and children peer support groups, a community hub.

- i. Reinforcement of a Community Development Network (CDN) at district and sector levels.** *The main role of CDNs is to serve a gatekeeping function in each sector. CDNs provide*

multi-disciplinary support to ensure appropriate placement decisions are made in the best interest of each child; prevent family breakdown and abandonment of children through identification, referral and support to vulnerable children, families and communities; seek alternative care where separation cannot be prevented, including through foster care; and monitor and support children in care or at risk in the community including those who are placed out of institutions. The CDN comprises of 36 members at district level, 449 members in 14 sectors and 360 members in selected cells.

- ii. Supported 46 vulnerable families with children with disabilities using the Active Family Support (AFS) model.**

This model is aimed at supporting children/children with disabilities reintegrated from institutions into family and community based care, children that are at risk of being separated with their families and children at risk of being placed in institutions. The interventions were planned in a way that benefits the entire family system in certain aspects of their life, through 5 domains: living conditions, family and social relationships, physical and mental health, education, employment and economy.

- iii. Establishment of 10 community volunteers to identify and support families at risk of separation with their children or families at risk of placing their children in institutions.** *Community volunteers have the mandate to support vulnerable families to form village based groups in order to prevent separation of children with their families or placement of a child in an institution. They are trained on Income Generating Activities (IGAs) to support vulnerable families increase their capacity to care for their children by enabling them to increase their household income.*

iv. Parents and children peer support group*In the area where the institution was located, there are more than 100 children with disabilities living in their families.*

The community assessment revealed that those children and their parents, specifically the mothers, lived in continuous stigma and discrimination while their children do not attend school. Hence, peer support groups for children were created to assist them build solidarity, feel valued, be recognized by society, and raise their voices against stigma. Through these peer support groups the children with disabilities explore and use their talent, advocate for their rights, local leaders recognize their needs and plan for a better future. Additionally, peer support groups for parents with children with disabilities were established to assist each other, share experiences, and create saving and investment platforms to assist with extra expenses incurred due to childcare for children with disabilities. The peer support groups are linked to local authorities for further support and assistance.

v. Development of foster care including specialist foster care. Abandonment is one reason for children to be institutionalized.

The reintegration team has been at the forefront of raising community awareness against stigmatization of children with disabilities and the benefit of raising children within a family-based care system. Foster care services were developed including specialist foster care in the area where the institution is located, and neighbouring communities. 13 special foster families were identified and trained; 5 among them welcomed in their families children with disabilities from Wikwiheba Mwana centre; they completed the guardianship process.

vi. Transformation of Wikwiheba Mwana into a Community centre. By the closure of the institution, Gatsibo District officials, NCPD, the institution

manager and Hope and Homes for Children agreed to transform the institution into an inclusive community hub which will serve more children, youth and adults including children and young adults with disabilities. The centre is currently operational with a range of services such as inclusive day care centre, physiotherapy, special needs education, occupational therapy, music as therapy and outreach activities.

vii. SMS technology; In collaboration with NCPD a technology of raising issues of PWDs was developed from village level to NCPD national levels. Gatsibo was among the districts where this service was piloted to serve a quick way of reporting and responding to issues raised by PWDs.

3.4. STEP 4- TRANSITION

Transition is the process undergone towards moving a child with disability from an institution to family and community based care. The process includes family tracing, child and family preparation, community preparation and placement.

Family tracing: the data collected from the initial child assessment on the birth and extended family, last carer, the person who brought the child to the institution are utilized to find the location of the child's family. The team conduct field visits to trace and meet the family.

This step is not necessary for children who are in contact with their families or those whose parents' location is known.

For the case of Wikwiheba Mwana, 23 out of 26 families were found during family tracing while information from the initial child assessment revealed only 10.

For the case of Centre inshuti Zacu initial child assessment revealed 8 out of 40 children with information on their families; but after family tracing we located the families of 21 more children.

Family assessment includes detailed information on the family. A standard tool is filled in by the case manager. This tool facilitates the collection of the following data on targeting the family as well as each family member: demographic data, age, sex, living conditions (accessibility checking, toilet and bed adapted for children with disabilities, primary carer for child with disability) family and social relationships, education and skills, behaviour, health conditions, household employment and economy.

The family is assessed through direct observation of family resources and environment. Family members are met and relevant information is collected and recorded, and further information is collected from community members including local leaders, members of extended families, and neighbours. At this stage, family needs, risks and potentials are identified. And the intervention is designed based on the needs assessed. This is usually followed by the placement decision.

Case Example: Support provided based on family assessment results/
Wikwiheba Mwana.

26 out of 26 families have been supported in terms of psychosocial support via parent group sessions, individual counselling, and family counselling to strengthen the relationship among family members and to secure the reintegration of a CWD.	14 families were given Income generating activities, 2 families were given cultivable lands, and 7 families were given livestock. These types of support were aiming at ensuring that families become more dependent on their own family resources based on the family strengthens.
14 families out of 26 families were supported to renovate the house to ensure the accessibility of children with disabilities in family setting.	5 families out of 26 families were supported to get a permanent residence (house purchase) to ensure that families of children with disability have permanent accommodation, and to avoid stigma from landlords who were not willing to rent their house to families with CWDs.
	All 26 families were trained on CWDs health support, for medication administration, basic physiotherapy, and how to feed and clean CWDs.
23 families out of 26 were supported with basic needs such as sleeping arrangements, chairs or mattress to ensure CWDs are placed in a more comfortable environment.	

Case Example: Support provided based on family assessment results/
Centre Inshuti zacu.

All of 16 families that received children from CIZ received support responding to basic needs for improving their living conditions: sleeping arrangement, basic amenities such as chairs and tables. Due to COVID -19 pandemic, 4 families received temporary food support	
All of 16 families received psychosocial support through parent group sessions, individual sessions, and family therapy to strengthen the relationship among family members for ensuring the welcoming environment for children.	6 families out of 16 were supported to proceed with civil registration for their placed children (guardianship, birth certificates and adoption)
	5 families received special training before placement in terms of continuity of care plan implementation for getting different skills of caring for their children (domestic physiotherapy :stretching, positioning, stimulation; feeding, washing and daily life activities according to children's disability).
	3 families out of 16 received house accessibility support and adjusted toilets for making their home accessible according to the children's disability.
6 families out of 16 were supported to access health services by paying health insurance for them and harmonization of their UBUDEHE level according to the new entry (child placed).	4 families out of 16 families received support for their house renovation targeting safe placement and a comfortable home with big and smart lightened rooms for their children.them and harmonization of their UBUDEHE level according to the new entry (child placed).
5 families out of 16 families were purchased houses for permanent accommodation because they were homeless and lived in high-risk zones.	
1 family out of 16 families received house building support and connectivity to water and electricity.	All the 16 families were linked to available community based mechanisms from village to district level, IZU, NCPD Coordinators, Community health workers, DMO to ensure the community monitoring of the CWDs placed with them.

Community assessment includes availability and accessibility to community resources (inclusive schools, health facilities, rehabilitation centres, day care centres for children with disabilities, special education, specialized services) to support and sustain the placement of children with disabilities. It is also relevant to identify and assess the availability of community structures such as community health workers, Inshuti Z'umuryango, NCPD structures, peer support groups for persons with disabilities, saving groups, CSOs supporting persons with disabilities, including churches. Community perceptions towards DI for children with disabilities is assessed as well, in order to prevent discrimination of a child with disabilities to be placed within that community.

Child and family preparation: preparation is one of key steps towards successful transition of children with disabilities into family and community based care. It is critical that children, parents, family members, community, local authorities understand and accept the importance of raising children with disabilities in families before any placement. This is done through individual and groups sessions, as well as psychological workshops with children, parents and family members including engaging the support of caregivers, facilitate visits of families to children into institutions and vice versa for children to families, and develop adjustment and intervention plans for children and youth to move from the institutions. Local leaders and available community resources are identified and prepared to support the placement and commit to monitor after placement, document all work done through case management report.

During child preparation, care plan development is designed and implemented for children with disabilities in the institution and continues to be implemented after the placement of the child.

Care plan development is based on the needs identified for children for them to

thrive. Care implementation is a set of actions to respond to needs assessed. This includes medical consultation, treatment, surgery, physiotherapy and other exercises aiming at stimulating children's development.

The following activities were used in Wikwiheba Mwana and Centre Inshuti Zacu to implement the care plan:

At home and in the institution:

All the below can be carried out by parents and caregivers.

- *Positioning in a comfortable stance and helping correct posture*
- *Changing position every hour*
- *Mirror play: mirrors are naturally attractive to children; they can observe own reflection, objects and light*
- *Playing with light and shadows on the wall/other surfaces – all you need is a light source and a surface on which you can project and observe shadows*
- *Reading: reading is very important for listening, imagination and ensures a significant (and enjoyable) contact with the child*
- *Singing together with children – also creates a safe and enjoyable medium for play and contact.*
- *Ball play – catching, tossing, throwing balls – good for eye-hand coordination, motor skills and lots of fun*
- *Massage - using oils – smells good and feels good; using a brush (like a hair brush or clean paint brush) on hair, hands, fingers and toes*
- *Play with materials for sensory stimulation:*
- *Experimenting touch with other materials: hard, soft, rugged, etc.*
- *Peek-a-boo, hugging and cuddling*
- *Creating a sensory crate: fill a plastic container or any other box (cardboard, shoebox with rice, corn flour, peas, sand, and pebbles.*

Provide a spoon and let the child play/ask to fill in various other recipients (smaller plastic bottles, sacks, socks, etc.)

- *Colouring games – crayons, watercolours (with brushes or fingers) or simply chalk. You can use paper, cloth, the tarmac, the fence, even the walls*
- *Building a tunnel – using a bedsheet you can create a labyrinth in the house, using chairs. Or you can use the tunnel to slide the ball through it back and forth.*
- *Parachute drop, you can hold a piece of cloth between two or more people and try to bounce a ball on the fabric without letting it fall.*
- *Building games: build towers out of plastic cups or playing cubes or boxes, then bringing them down with a ball, a kick or a hit with the broomstick*
- *Music play – use musical instrument where available. If not available use drumming on plastic bottles, chairs, tables, etc. Or use plastic bottle as trumpets. Compose a song using only materials you have in the house as musical instruments.*
- *Water play*
- *Making soaps balloons – mix a little soap with warm water really well, then use a small circle made out of thin wire to blow balloons. Or just make balloons anyway you can!*
- *Playing in the sand. You can replace sand with regular soil.*
- *Dancing*
- *Sports. Create your own sports competitions adapted to the abilities of children.*
- *Playing with puppets – make your own puppets using stuffed old socks, or simply pull the socks on your hand, draw something funny on them and have a play. You can even make balls out of old socks.*
- *Use of the old toilet paper tubes to colour them with crayons or paint, or cut them into shapes.*
- *Have a picnic – either outside, or indoors.*

- *Involve children as much as they are able in household chores – dusting, sweeping floors, washing dishes or simply indicating where they want their clothes arranged.*
- *If you have a garden, take the children into the garden and let them play or plant.*
- *Make a collage from newspapers or draw your animal collection.*
- *Pronunciation exercises: try to pronounce as clearly as possible various sounds*
- *Self-feeding practice – using either fingers (when eating fruit or biscuits) or a spoon*
- *Learning colours, numbers, letters*

All activities should be adapted to the physical and cognitive needs of each individual child.

During family preparation, the first contact with families showed fears to welcome back and raise their children. Those fears were around capacity and skills to care for children with disabilities, where/how to have access to specialized schools, health services, means, and time to care for children with severe disabilities. Families believed that institutions provide all these services.

In Wikwiheba Mwana and Centre Inshuti Zacu, family members were invited to visit children in the institution and spent time with care givers to see how they are fed, washed and played with, in order to stimulate learning but also to demystify the beliefs on the care of children with disabilities within institutions. Family members found that everything done by care givers in the institution can be done also by parents at home.

Apart from activities done with children to implement the care plan, there are various other factors considered before placement of children with disabilities in family -based care. These include working with specialized services, such as Gatagara HVP (Le Home de la Vierge des Pauvres), Ririma Hospital,

HNP (hospital Neuro Psychiatric) Ndera, centre Ikizere for medical and educational assessment on skills and capabilities of children with disabilities. Diagnosis was decided and treatment provided including surgery, assistive devices for children with disabilities.

Family Capacity: we ensured the family has the capacity to take care of a child with disabilities without the child becoming a burden. Supported families to meet basic needs (meals, shelter, appropriate toilet, wheelchair, and accessible facilities) for a successful reintegration of children.

Existing community services: identified community services that support inclusive education and health services.

Community awareness: conducted community awareness to mitigate stigma and discrimination towards children with disabilities and their families.

Training: conducted training for special foster carers so that they are more skilled to care for children with disabilities and deliver prevention services.

Strong collaboration: collaborated with stakeholders including NCD Agency, NCPD, and district authorities to provide guidelines on the best approaches of closing an institution and reintegration of the children with disabilities into family-based care.

Placement of children and adults with disabilities into family and alternative care solutions, such as birth family, adoption, extended family, guardianship, independent living and other family like settings. The placement of the child into a family is not the sole responsibility of the case manager.

Local authorities from the sector where the institution is located as well as the sector where the child is being placed are involved.

The exit form is signed by the institution management, executive secretary of the sector (where the institution is located and where the child will be placed), the family and the case manager.

The placement decision is made by a case management meeting composed by a multidisciplinary team of psychologists, social workers from NCD Agency, Hope and Homes for Children and institution staff.

The option of placement prioritizes the level of the child's affiliation to the family respectively biological, extended family, adoption and guardianship; however some adults can be placed in independent living.

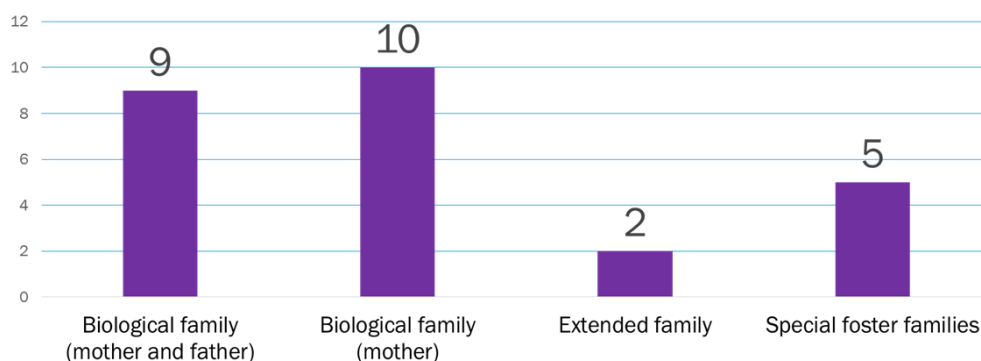
Placement of children with disabilities from Wikwiheba Mwana and Centre Inshuti Zacu Institution as of March 2021.

Fears, worries identified, and responses provided during different steps above mentioned DI steps are in annexes of this document.

Types of placement	WM	CIZ	Total
Biological family	19	8	27
Extended family	2	3	5
Guardianship	5	2	7
Independent living	0	3	3
Total	26	16	42

Case Example 6. Placement of CWD from the closed center Wikwiheba Mwana

Only 21 children were able to return to their families while 5 were placed into special foster care.



After placement, depending on the children's needs, they were linked with Inshuti z'umuryango, community health workers, NCPD structures, peer support groups, local authorities, health facilities, schools, specialized services, and CSOs, including churches. This was done to create a supportive and protective environment around the children, so as to avoid further separation.

Cost of reintegration of a child with disability

The cost of reintegration of children with disabilities varies depending on many factors, including the type of disability, living conditions of the family, possibility to attend formal school or vocational training, medical check-up, and treatment, etc. For the two pilot centres, the cost of reintegration ranged between 135,000 RWF to 8,000,000 RWF for all 42 children with disabilities excluding postplacement support and other logistics costs (see detailed costs of reintegration for all children from Wikwiheba Mwana and Centre Inshuti Zacu in annexes).

3.5. STEP 5 - MONITORING AND EVALUATION

The monitoring and evaluation (M&E) component is crucial at each stage of the DI process. This step is done through post placement follow up of children transitioned and families supported to ensure children's safety and wellbeing.

Monitoring includes home visits, individual and group sessions with children and parents, on-site training and mentoring of parents on parenting, linkages with community resources such as community volunteers, local leaders, specialized health facilities, schools, CSOs, NCPD structures and peer support groups. The evaluation includes child and family re-assessment to identify gaps and see the child and family progress after reintegration.

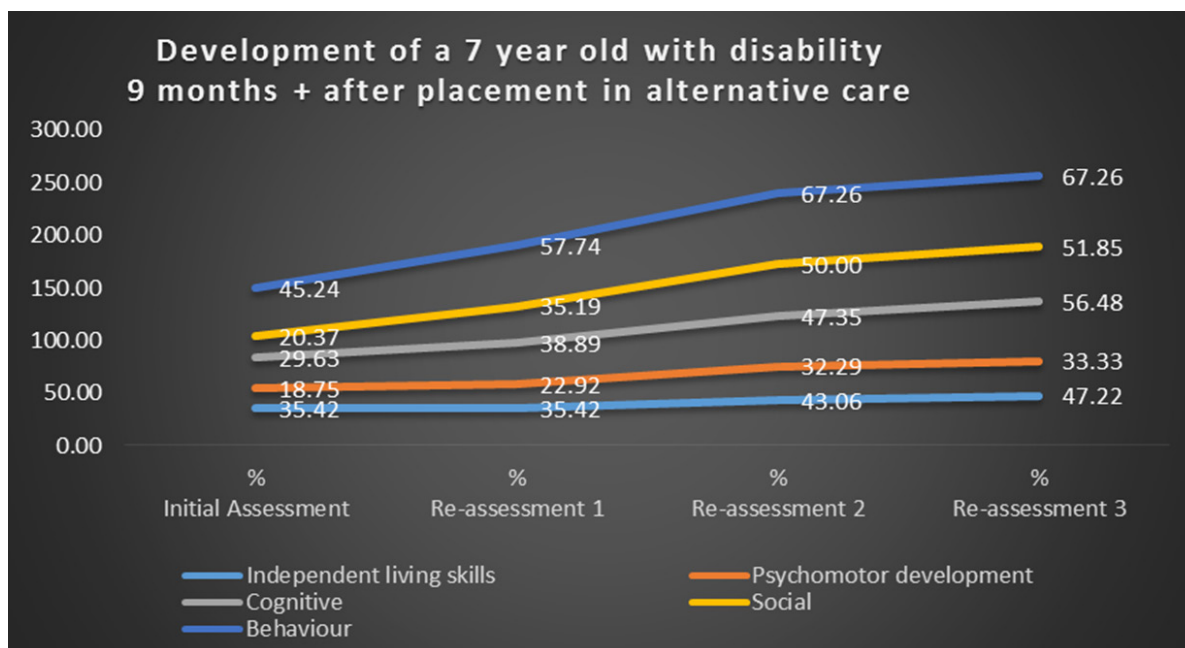
The M&E framework allows existing mechanisms to coordinate services in the interests of the reintegrated children and their families. Concerned Government officials also contribute to monitoring efforts by visiting families to ensure that the best interests of the child have been fulfilled.

Post-placement support

1. *Follow up of reintegrated children with disabilities and their families through home visits and phone calls.*
2. *Follow up on the effectiveness of support provided to families.*
3. *Collaboration with identified key persons in the community supporting the family (local leaders, extended family, neighbours, health facilities, community volunteers, etc.)*
4. *Children/Parents/foster care group session*

Example of findings for a 7 year old with disability assessed using B+C scale Profound Disability at third re-assessment.

The results of the assessment of one child with disability, using B+C scale for profound disability, in the chart below, indicate a mean increase of 21% across all the development indicators, from 30% at initial assessment to 51% at third reassessment after 9 months spent in a family. Social development increased by 31% followed by cognitive development at 27% increase. Behaviour development indicated an increase by 22% while psychomotor development increased by 15%, as development of independent skills increased by 12%.



The assessments were conducted over time. In addition to the above evidence, some indicators of successful reintegration of children with disabilities into family-based care include:

- Resilience of parent(s) to acknowledge and care for their children with disabilities, including extended family. Having a positive mindset and capacity to afford expenses of all the children;
- Preparedness of the community and leaders to support and contribute to the transition process together with the family;
- Linkage to community opportunities and development programs like Girinka, shelter support and other grants;
- Linkage to community resources like health facilities, schools;
- Preparedness of the children with disabilities to adapt to family situation including interactions with family members and neighbours;
- Registration of the child with disabilities in the sector civil register, guardianship or adoption by the foster parent;
- All DI steps have been followed and completed.
- Positive feedback from child and families on how children with disabilities are coping within their new settings;
- Accessibility to specialized services such as inclusive schools, health facilities, day care centres, CBR

4. CASE MANAGEMENT

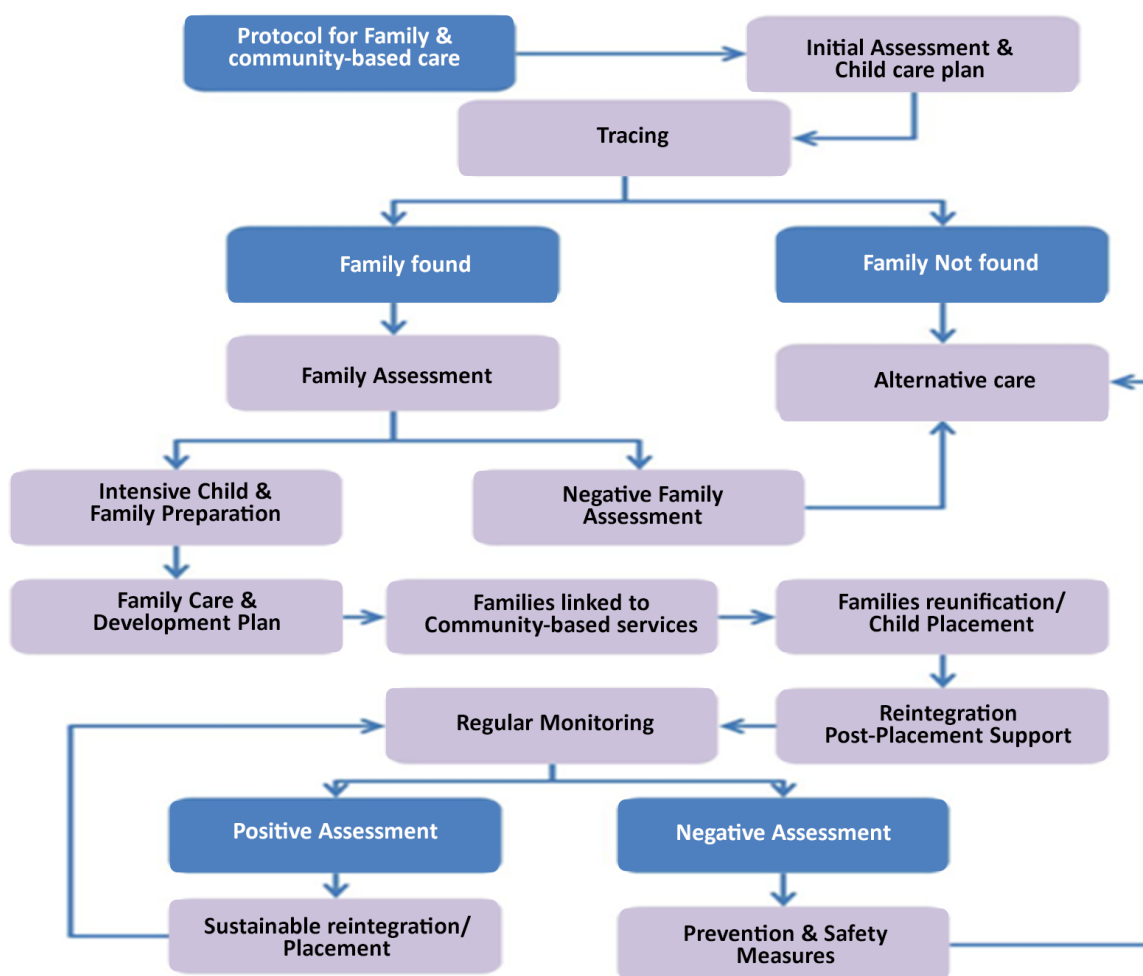
Assessments are considered an integral part of the DI process in order to inform decisions on the appropriate

case management approach. Case management is a process of individualized and time-sensitive mechanisms that start with early detection, to providing support (intervention), making referrals across sectors and services, follow-up, and closure. The role of the professional is to assess needs, resources that inform

the design and management of the intervention.

Although Case Management with a family focus involves understanding and responding to each child's individual needs, the needs and vulnerabilities are not independent of those from other family members, and the response to the individual child should be delivered together with a response to the family as a whole.

Case Management Procedure



5. TOOLS USED FOR DI OF CHILDREN WITH DISABILITIES.

Various tools were used during the case management process. Some are filled in before the placement of the child into family-based care and others are filled in after placement into family based care. The table below shows the list of tools used:

Tools used to transition children with disabilities in family and community based care.

Tools used before the placement into family based care	After placement into family based care
<ol style="list-style-type: none"> 1. Registration form 2. Initial assessment for the child 3. Initial Psychological assessment 4. Family tracing report 5. Proof of no trace found for family 6. Refusal of child by the family 7. Initial Assessment for the family 8. Individual Care and Development Plan 9. Case management 10. Child and Family Preparation 11. Child protection risk assessment 12. Intervention Plan 13. Adjustment Plan 14. Exit form 15. Contract - Child's Placement into the family/independent living 	<ol style="list-style-type: none"> 1. Post-placement support and follow up 2. Post-placement Intervention (same doc) 3. Child psychological re-assessment forms (Portage, SPDS, Special needs) 4. Family re-assessment forms 5. Proof of support to the family (financial/material with receipts) 6. Child protection risk assessment 7. Case management checklist 8. Case Closure

6. SOME SUCCESS STORIES

Alice reunites with her family after seven years of living in an institution!

Alice was born in 2012 in Gakenke District. Alice was placed in the institution on 1st July 2013 after the death of her mother. She has verbal difficulty and limps due to physical disability on both legs. She is able to feed herself but has difficulty in verbal communication. In the institution, Alice's self-care skills were poorly developed as she was not able to take a bath by herself, wash simple under -garments and needed assistance for personal hygiene. Alice spent 7 years in the institution. Her father, Emmy, is serving a 25-year prison sentence, while her mother, Anita, died while giving birth to Alice. Her father remarried and had another child with his new wife.

The preparation process was collaboratively done by a case management team composed of NCD Agency (TMM staff), institution care givers, Hope and Homes for Children staff, and the person responsible with social affairs at sector level. The preparation process took 6 months.

The team met with Alice's stepmother and relatives who wanted her returned to her family, as recommended by Alice's father. The team then visited Emmy, Alice's father, in prison, who confirmed that his daughter must be cared for by her stepmother together with the other children (Alice's siblings).

During this process, the team discovered that the family had a property related conflict, which was causing resistance to Alice's return home on the part of the extended family. With the support of local leaders, the team worked with the executive secretary and the social affairs officer at cell level to resolve and reconcile the conflict in the family.

During the family assessment, it was discovered that the family house was too old, located in a high-risk zone (prone to disasters) and inappropriate for a child with disability, while all their neighbours were relocated to an approved settlement. As a result of the case management conducted, a house was purchased and other household items for Alice's family.

On 24th July 2020, Alice was placed into her biological family and welcomed by her stepmother and two brothers.

As part of the post-placement support, Alice was hospitalized at Ririma hospital (Center of Surgery and rehabilitation), to receive intensive physiotherapy for two months. She was later transferred to Ruli district hospital for continued physiotherapy support.

With the support of her stepmother, Alice started attending school (P1) only in the morning, in order for her to attend to the 3 recommended physiotherapy visits per week in the afternoons. The professionals also linked Alice with local authorities, inclusive school, and health services which she has begun benefitting from.

Professionals continued to provide psychosocial support and covering Alice's medical expenses. Alice's daily life is monitored by the village leader, the sector NCPD coordinator, IZU and community health workers.

The re-assessment after 6 months showed remarkable improvement for Alice in terms of autonomy, ability to peel potatoes, wash simple clothes, and clean parts of her body.

Aline case: none could think she can learn something now she is helping out with domestic tasks!

Aline is a young girl born in 2009 in the eastern province of Rwanda in NYAGATARE District with mental impairment, she is on the autistic spectrum with epileptic tendencies. Both her biological parents were suffering from mental problem. She has one younger sibling.

In 2009, at the time of her birth, both of her parents were mentally healthy, but they were using strong drugs which led to their mental problems.

Her father was a barber, and her mother was a cook in a restaurant. They lost their jobs and the means to pay for their rent, became homeless and started begging on the streets with their two children. Both parents would eat food from friends who knew them before they got ill. The young child was 2 years old and Aline was 4 years old.

After a certain amount of time on the streets, the mother of the children became desperate and left the father together with the two children, begging on street. One of the neighbours, who was passing by, took the youngest and brought her to his place, but he was not able to take care of two children. Aline continued to live on the streets with her father for 2 more years, surviving with her father, being fed by the good people who were so kind to give them some food. They would sleep on streets.

One day when a priest was passing by, he saw a child together with her father, a very dirty child. He saw a child who could not say a word, who had cognitive development delays and a father who was sick, who couldn't look after her, and he has decided to bring the child in an institution for children with special needs.

The child was brought to Wikwiheba Mwana when she was 6 years old, in 2015. At arrival in the institution, the priest reported that he had asked her father if he could take the child away and that the

father had accepted.

Once in the institution, she was taken to the hospital, she was diagnosed with epilepsy and she was put on medication. She was not able to speak, and she was placed among other children who suffer from different disabilities. In the institution she was a child who stayed alone, doing her own things, no one would care asking her what she wanted. She would spend an amount of time running around in the institution, doing whatever came to her mind.

Nobody in the institution would take time to teach her any skills. She would see caregivers folding clothes and she would repeat the activity alone in her room with her clothes. She was a child who was clean and would not get herself dirty, she wanted always to be clean. She was not able to say a word or to focus on a certain activity to finish it. Aline spent 4 years in the institution.

Hope and Homes for Children staff traced her biological family, and they found the father of the child on the street, collecting plastic bottles to sell them to feed himself. He was still homeless. They tried to speak with him, but he was not able to put together any coherent ideas. They then approached other barbers who had worked with the father before, and they said that they had known him for a long time, and he had become homeless, and he could not look after himself.

The team asked the barbers if they knew where the mother had gone and they responded that nobody had seen her for years, she disappeared. Nobody knew where the couple was from either. Local leaders were involved during the family tracing, and HHC staff failed to find the mother or any of the extended family. They failed to find the couple who took in the younger sibling of Aline as well, because they had moved from the eastern province

and nobody knew where the couple was living now.

Thus, HHC staff started to prepare a special foster family to receive Aline. A couple of Wikwiheba Mwana former staff accepted to take the child in September 2019. She joined a couple that have three children, two daughters and one boy, the eldest child is of the same age as Aline.

Before the moving, Aline was having a short attention span, she would spend a significant amount of time walking around in the institution without any defined focus, doing anything that came to her mind. Now, she can sit and be more focused and spend time with family members. Even when visitors are around, she sits together

with other children in the family. She has now learnt some new skills, like fetching water together with the other children, she has learnt to wash herself, she can now feed cows at home and help with some small domestic activities, and she can call the mother of the family “mama” as she hears other children calling her. She can say the names of some other family members, she can repeat songs she is hearing the other children sing, but she cannot speak a lot of words. She can help in the kitchen, washing dishes. She has been brought back to the hospital and she received another prescription.

She has been enrolled, among other children with special needs, to attend the day care center at the Community hub that the institution was transformed into.

After being reintegrated in family based care, AIMABLE has realized one of his big dream !

AIMABLE is a young boy of 15 years old. He is the firstborn of 3 children in his family. He was born with a physical disability. He was born with cerebral palsy. Both of his parents are alive.

After birth, his parents took him to several hospitals searching for medical assistance. Parents were observing that their newborn was not having the proper development as their other children, he was not gaining the use of his hands, the use of his legs, he was not standing at 1 year of age, he was still crawling, and parents were observing that their child was not holding properly something in his hands.

So, the parents decided to take the child to a different hospitals to search for medical support to address the gaps the child was displaying in terms of physical development. The parents were hoping in vain to see a change. As they were still looking for medical support, they heard of an institution that can provide education and medical assistance for children with disabilities, so they brought the child to the institution in 2013. Hoping that he will

have the support they were desperately looking for. The child joined the institution when he was 8 years old.

Once in the institution, he started primary school at a neighbouring school, and he formed a good relationship with other children in the institution. In the institution he did not lose contact with his parents. They were coming to visit him often in the institution and the child was visiting them at home during holidays.

He was still connected to his two other siblings. The child had mentioned once that he sometimes misses his parents and his siblings. He was a bright child, he was appreciated by caregivers. Though it was very difficult for him to speak, he loved so much to share stories, yet he was not satisfied because he was not getting people who would share with him the passion he was having. He developed this passion from his parents, especially his father, who would spend evenings sharing stories with his children.

Despite his disability, he managed to follow inclusive normal education. He was able to sit, bring himself to the toilet, and speak, though that was very difficult for him.

Aimable had spent 5 years in the institution, and he joined back the family in November 2018.

Professionals prepared the family to receive him from the centre. For the parents, it was not an easy thing to take back their child. They didn't fully understand the re-adjustment they were about to do at home. As the child was asking to go back home, they accepted and supported the idea.

The parents were convinced that they are making the right decision, mainly because the child was showing them that he needed their support with school, to sit the national examination. Both his parents are teachers.

He was reintegrated into his family when he was in P6. One of the great challenges was how he would sit for the National examination so that he can pass secondary school.

The headteacher mobilized teachers to help the child at school and within his classroom. The school supported Aimable to succeed. Some students helped him to take notes and teachers were paying attention to his challenges as a student with special needs. After a year, he proved that he was able to sit for the National Examination.

It was the first time a child with special needs was in need to sit for the National Examination in the school. Thus, the school headmaster wrote a letter to the Director of Education in the district, requesting proper attention for the child to be able to sit in the National Examination. The Director of Education advocated for the child at the Rwanda Education Board at the National level. The Rwanda Education Board mandated a team to assist the child during his National Examination. He was using verbal communication to respond to questions and the team was assisting him to write on the examination paper. It was an extraordinary event to see a child

with disabilities, especially a child who cannot write on his own to sit the National Examination. For the district authorities, it was a success to assist such a child. The vice mayor in charge of social affairs went to observe the event together with the media. It was a huge event. The mother said:

"I was present, none was allowed to see AIMABLE, only the vice mayor has entered where he was doing his examination, it was amazing to see my child being visited by the Vice mayor during his National Examination".

For the District, it was a step ahead in the implementation of inclusive education in the district.

Aimable passed the exams successfully and was admitted into another school. However, his mother preferred that the child stayed at the school where he was studying because of the support he was having from teachers, everyone was used to see and help Aimable.

Now he lives with his family, he studies at the Secondary level at the neighborhood school. He is very happy to live with his family and his siblings. His mother is the one who looks after him, mostly. The father has a bike and he brings him to school and then goes off to his job.

Still, the school was a bit far from home, and the mother requested a transfer to another school, which is nearby the parents' home, so that it is easier for the parents to look after the child and to bring him to school. We have then requested the Director of Education to facilitate the change and the mother has also been transferred to the same school nearby her home, as it will be easier for the mother and the child to go to the same school. The local leaders at the district and sector level supported the child and the family and the school built an adapted toilet for the child to use while at school.

Aimable likes the fact that he plays with his siblings, he has gained new friends at school, and he has a good

school performance. His parents are very supportive of his education. In the evenings, the father helps the child to do his homework and to review his subjects. His teacher said that he has good school performance and he follows quite well at school. The teacher has mobilized other pupils to help him taking notes in class. The father said:

“Though there are challenges, we are facing them on a daily basis, we are glad that we are no longer worried about the well-being of our child, when he was in the institution we were often worried of how the child is”.

The mother, together with the NCPD (National Council for People with Disability) at the Sector level, pledged to start a group of parents of children with disability in their communities for peer support.

Aimable had dreamed to release a song, it was one of the things he wanted to accomplish in his life. When HHC staff visited the child recently, he had two songs, one was a song against COVID-19, and another was a song about the right of people with disabilities. We have proposed to bring the child to the studio to release the song. The mother laughed so hard, as for her it was unbelievable that he could record and release a song. We have told her that it is something possible. We have requested her to come with the child to the Studio. Then, they recorded and released a song. After the song was released, Aimable was so happy that he declared that he now has fulfilled one of his dreams. There is another project in perspective of releasing another song where he is singing the mission and vision of Hope and Homes for Children.

7. LESSONS LEARNED FROM THE TRANSFORMATION OF CIZ AND WM INSTITUTIONS

Some learning to consider during the next closure of institutions for children with disabilities:

1. Engagement with the sisters in the second target institution (faith-based institution) required more time than expected and revealed to be non-stop.

They work in a complex system with many decision makers whereby a decision taken on one day might change on another day. Full ownership of the process is key for faith-based institutions to allow for professionals working with children within the institution. An increased level of engagement meetings with not only the institution manager, but also with the board members and superiors, to ensure we have their support, while respecting their hierarchy is extremely important. This will inspire future engagement of institution managers for institutions to be closed and transformed.

2. HHC Rwanda secured a MoU with the NCPD to pilot the closure of 2 institutions for CWD and support prevention activities with a focus on CWD.

This also includes an agreement to build the capacity of NCPD professionals based at district level to support CWD in families and alternatives. We learnt that with the government's willingness to collaborate and support DI for CWD, comes an easier and smooth implementation process. Our partnership allowed their support to DI for CWDs and has contributed for the engagement of other stakeholders towards childcare reform including CWDs. Our collaboration engagement has unlocked the resistance of the institution manager for the second institution closure.

3. Post placement visits revealed that families of CWD need a substantial amount of financial support for medical treatment for the children.

Visits to CWD after placement from institutions revealed that they can develop their potential if appropriate medical care is provided on time. One of the challenges identified is that most of the families visited do not have financial capacity to cover medical treatment for their CWD, indeed they cannot afford medical treatment costs and transport from their homes to hospitals. After identifying the challenge, HHC advised the disability mainstreaming officers (DMOs) at district level during their refresher training to advocate to different partners operating in their districts to ensure they support CWD focusing on medical treatment, as HHC alone cannot afford to cover medical treatment for all CWD in need. DMOs were also advised to continue advocacy efforts in their districts to increase their budget for supporting PWD and advocate the government so that specialised hospitals may consider health insurance for the treatment of PWD, especially CWD.

4. The importance of adequate preparation and engagement:

Institution owners, managers and staff need to be integrated in the DI process because they have the trust of the families. Despite the long processes of negotiations that may cause delays in implementation, it is important to use evidence during stakeholders' engagement in order to limit resistance and fear of caring for a child with multiple disabilities from the primary stakeholders (families, children and institution managers).

***“Family reintegration is possible:
What caregivers can offer in the centre,
parents can also...it is a matter of
preparation and training if necessary”
(Institution staff)***

5. Linkage with community structures and services:

Each case deserves adequate attention and appropriate referral based on the need. Linking children with disabilities and families to specialized services within the community is crucial in ensuring sustained wellbeing of the children with disabilities. Important linkages should include medical facilities, inclusive schools, local leaders, and frontline volunteers, including IZU, community health workers. Working with different community structures and services facilitates the adoption of monitoring efforts for the children.

6. Cost of reintegration:

The cost of reintegration of a child with disability is higher than that of a child without any disability. Budgets need to be adjusted to reflect the emergent needs for children with disabilities' placement. Considerations should be made in

relation to the high cost of specialized medical treatment, the high cost of improving family environment (house renovations and purchase for permanent accommodation) associated with limited community resources, preparations and training of families, parents and teachers on how to take care of children with disabilities. For instance, parents and teachers (from schools that the child would attend) are supported to visit the institution or specialized hospital in order to learn how to take care of a child with disability, including basic physiotherapy.

7. Advocacy and mobilization:

Given the cultural perception towards disability, there is a number of children with disabilities who have not been identified within the communities and are not accessing needed services. There is a need for advocacy and mobilization of the communities in order to screen and identify children with disabilities, as well as to create awareness on issues affecting children with disabilities, seek solutions to the challenges, and provide appropriate support.

8. FACTORS WHICH CAN CONDUCT TO PLACEMENT BREAKDOWN

Successful reintegration is not always the case. Where there is a failure, the case management team re-starts the process following the placement procedures. Ethical decision helps to cope with the stress associated with failure, as some families will not welcome a child with disabilities.

Some factors of failure include:

- Placement without child protection risk assessment within the host family
- Rushing the child and family preparation
- Inadequate preparation of some family members due to their absence during preparation sessions
- Placement decision based on family financial capacity without considering other aspects.
- Placing the child without consulting extended family, community members' views.
- Pre and post placement sessions with families regarding children's behaviours not well conducted
- Primary care for a child with disability not well determined
- Placing a child with disability to parent without parenting skills
- Parents unable to cope with child's challenging behaviours
- Misuse of financial support provided
- Family conflict
- Family motivation to receive a child not well assessed.
- Lack of regular post placement follow up.
- Lack of individual session/conversation/dialogue with the child without the presence of family members during post placement visits.
- Lack of community support and services (schools, health services, social welfare, play groups, home based ECD, peer support groups etc.) associated with parental fatigue to care for child with multiple disabilities.
- Lack of community consultation during post placement follow up.
- Low involvement of local leaders.
- Discriminative community.

9. STAKEHOLDERS' PERCEPTION ON THE REINTEGRATION OF CHILDREN WITH DISABILITIES IN FAMILY-BASED CARE

Although not all children with disabilities will be reintegrated for various reasons into family care, it is important that all children live in families, so that they can experience the love and warmth of parents or caregiver. Children with extreme and multiple disabilities will need special care in well-equipped and managed centres, that meet minimum standards, while the reintegration of children with disabilities into families will need to be gradual, ensuring that the minimum services will be offered by the family and the community.

10. SUSTAINABILITY: PERCEPTION OF HHC INTERVENTION

Sustainability of DI is planned at the commencement of the process where different stakeholders are engaged to ensure acceptability of interventions. The government of Rwanda plays an important role in ensuring initiatives are sustained within families and communities. HHC ensures that support is provided to centres to allow adaptability to reintegration plans while allowing parents and partners (districts, donors) to contribute to centres.

The transformation of institutions into sustainable initiatives, such as the Centre Wikwiheba Mwana conversion into a model of inclusive ECD, should be done with district involvement. It is also important that the community is involved at all stages of DI in order to value children with disabilities and own the process.

11. CHALLENGES

During the process of pilot closure for institution of children with disabilities, different challenges were encountered:

At Engagement step:

- Fear of the feasibility of DI of CWDs that refrained the involvement of some stakeholders and led to changing the commitment of some stakeholders depending on the cases of CWD.
- Some partners remain very sceptical about the DI process and its potential to succeed.
- High resistance of institution manager and staff and low engagement
- Fear of institutional staff for loss of employment due to DI

At Assessment step

- Lack of data on children and young adults with disabilities
- Inaccurate data about children with disabilities especially exaggerated numbers, wrong background information on each child
- High vulnerability of children and young adults with profound disabilities.
- Inadequate/inaccurate information on care plan for each child in the institution

- Inadequate/inaccurate information on care plan for each child in the institution

At Service design and development step:

- Stigma and discrimination in the community
- Inclusive education is elusive. Not all schools have facilities to allow dealing with CWD
- Lack of qualified workforce in the community to follow up/link children with disabilities and existing services.
- Lack or low quality of specialized services in the reformed centres

At Transition step:

- Expensive process with many unforeseen and urgent expenses
- The reintegration process is complex due to a large multidisciplinary case management team with different expectations and needs.
- Difficult to know the motivation of some foster families and extended families.
- Education access (physical) and inclusion remain a challenge for some children with disabilities.
- Uncertainty of the future for children and young adults with disabilities who need permanent care.
- Long term support is needed, and decisions made on their behalf.
- Medical facilities lack the treatment and medication for some conditions children with disabilities suffer from.
-

At Monitoring and Evaluation step:

- Complex post-placement support due to inadequate existing services at health facilities to offer appropriate physiotherapy and medicines (only provided by NDERA Psychiatric hospital)
- Poor mindsets and myths about raising CWD in the family, leading to abandonment, including changing of home address to avoid being traced; thinking that the institution will heal disability; looking after a CWD is seen as a burden and a waste of time.
- Economic difficulties faced by families while taking care of a CWD.
- Dependency of certain families makes them fail to find their own solutions to challenges.

12. EFFECTS OF COVID-19 ON THE REINTEGRATION PROCESS

The COVID-19 pandemic has affected the reintegration process in various ways, including:

- COVID-19 has been prioritized over the reintegration process, leading to delays.
- Economic conditions of families have been negatively affected as capital for IGAs or funds for renovations were diverted to meet basic needs, such as food.
- Difficulty to hold case management meetings as physical contact was not allowed.
- Children with disabilities became

victims of endless pressure because of the economic and financial shock.

- Dramatic increase of costs causing delay in DI implementation.
- Inaccessibility of health and medical care for chronic conditions

Coping mechanisms to face challenges related to the Covid-19

The main coping mechanism was to slow down the process of placement and establish solid linkages with local authorities to support urgent needs of the placed children with disabilities and their families. Other mechanism are as follows:

- Children and young adults to remain in the institution until the process is done properly and receive food and other support.
- Specific advice to children with disabilities on covid related limitations and measures.
- Use of electronic transactions like Mobile Money payment and bank transfer to provide support to families (safer payment mode).

Positive lessons learned from COVID-19 related restrictions to the DI process include:

- Ownership of the process: Due to movement restrictions families and local authorities have been more involved in the wellbeing of children with disabilities. District hospitals supported by decentralizing their services to Health Centre facilities
- Increased in linkages: Linkages to the community and local structures improved. Frontline volunteers and local authorities took more responsibility in the DI process.

13. REFERENCES

1. Babbie, E. and Mouton, J. (2001) the Practice of Social Research. South Africa Oxford University Press, Cape Town.
2. Carter, R., Family Matters: A study of institutional childcare in Central and Eastern Europe and the Former Soviet Union, Everychild, 2005.
3. Chiwaula, L., Dobson, R., Elsley, S., Drumming together for change: A child's right to quality care in Sub-Saharan Africa, SOS Children's Villages International, CELCIS, University of Malawi, 2014.
4. Csáky, C., Keeping children out of harmful institutions: why we should be investing into family-based care, Save the Children, 2009, p 3.
5. Faith to Action Initiative, Children, Orphanages, and Families: A summary of research to help guide faith-based action, 2014.
6. GoR, USAID & UNICEF. Evaluation of the Tubarerere Mu Muryango (Let's Raise Children in Families) Program in Rwanda, Phase 1: Summary. Rwanda, 2017.
7. HHC, notes on Institutional care, 2021
8. http://www.genecold.free-online.co.uk/book-sandra/page_13.htm
9. <https://bettercarenetwork.org/library/principles-of-good-care-practices/transforming-institutional-care/evaluation-of-the-tubarerere-mu-muryango-lets-raise-children-in-families-program-in-rwanda-phase-1>
10. https://bettercarenetwork.org/sites/default/files/1.Global%20Numbers_2_0.pdf
11. https://pureportal.strath.ac.uk/files-asset/66699664/Milligan_etal_2016_Alternative_child_care_and_deinstitutionalization_in_sub_saharan_africa.pdf
12. <https://www.hrw.org/news/2017/03/07/children-disabilities-deprivation-liberty-name-care-and-treatment>
13. https://www.openingdoors.eu/wp-content/uploads/2014/11/DI_Lessons_Learned_web_use.pdf
14. K. Browne, The Risk of Harm to Young Children in Institutional Care, Save the Children, 2009, pp. 9 – 17.
15. National Institute of Statistics of Rwanda (2012). Rwanda Fourth Population and Housing Census (RPHC-12)
16. National Survey of Institutions for Children in Rwanda, MIGEPROF & Hope and Homes for Children, 2012
17. NCPD et. Al (2016) National Assessment of Centres caring for Children with Disabilities in Rwanda
18. OHCHR, Forgotten Europeans, Forgotten Rights – The Human Rights of Persons Placed in Institutions, 2011,
19. Rwanda Ministry of Health (2018). Violence against Children and Youth with Disabilities in Institutional Settings in Rwanda: A qualitative study. Kigali, Rwanda.
20. UN General Assembly, Guidelines for the Alternative Care of Children: resolution / adopted by the General Assembly, 24 February 2010, A/RES/64/142.
21. UNICEF, Children and Young People with Disabilities Fact Sheet, 2013
22. UNICEF, deinstitutionalization for children with disabilities: technical guidance for UNICEF's engagement in national reform efforts, 2019

14. APPENDICES

Appendix 1. Questions & Answers



Republic of Rwanda
Ministry of Local Government



**NATIONAL COUNCIL FOR PERSONS
WITH DISABILITIES**

**ANSWERS TO FREQUENTLY
ASKED QUESTIONS RELATED TO THE
REINTEGRATION OF CHILDREN WITH
DISABILITIES**



hope and homes
for children



ANSWERS TO FREQUENTLY ASKED QUESTIONS RELATED TO THE REINTEGRATION OF CHILDREN WITH DISABILITIES



Republic of Rwanda
Ministry of Local Government



**NATIONAL COUNCIL FOR PERSONS
WITH DISABILITIES**



**hope and homes
for children**





FOREWORD

After the reintegration of more than three thousand children (3000) including children with disabilities who were catered for in institutions, the country had to plan also how children with disabilities living in various institutions could also enjoy their rights to live in families through the “Rwanda Child Care Reform Program”.

Quite often, people wonder if children with disabilities who live in institutions can be catered for in families. Most of them focus on the nature and complexity of the disability, they express serious concerns that families will not be able to take care of these children and maintain them in good life.

The aim of this document is to provide detailed explanations on frequently asked questions related to the reintegration of children with disability in families.

NDAYISABA Emmanuel

Executive Secretary of the National
Council of People with Disabilities





1. Are there institutions that cater for children with disabilities in Rwanda?

Yes, there are institutions that cater for children with disabilities. There are institutions that provide medical care, others that provide education Support and others which cater for children with disabilities as permanent residence.

This document focusses on institutions that cater for children with disabilities as permanent residence. The admitted children may have known biological families or not.; even if these institutions provide some of the services mentioned above such as medical care, kinesitheraphy or education support. In 2012, the Government initiated the Rwanda Child Care Reform. In order to support the implementation of this strategy, the Government of Rwanda in collaboration with UNICEF initiated the Let's Raise Children in families programme in 2013 ***bearing in mind the fact that every child, with or without disability, has the right to be raised in a loving family.***

2. Many children living in institutions caring for children with disability do not have families. Where will they find a family that is ready to welcome and meet their basic needs without expecting any benefit?

From the experience of the reintegration of children in general and the reintegration of children with disabilities such as Wikwiheba Mwana Institution, 73% of children raised in institutions had at least one parent or both while 8% had extended family members. These figures give hope that many children will return in their families and continue to enjoy the love of their parents and siblings. On the other side, 19% of children in the institutions had no families at all.

Hence, the remaining solution would be to identify Foster families commonly known as “Malayika Mulinzi=Guardian Angels”. Malayika Mulinzi are foster parents who freely volunteer to provide custody or guardianship to children whose parents died or unable to look after them. They do not expect any Benefit and their decision is purely for humanitarian purpose.

3. Is the reintegration of children with disability really possible? How is it done?

The reintegration process for typical children is the same for children with disabilities.





How is the reintegration process conducted?

The first step is to gather sufficient information on the child and his/her family through family tracing. This step helps to identify children who have a family and others who do not have a family. Once the family is found, its assessment follows in order to find out if it has the will and means to take care of the child with disabilities. Then, the preparation of the child and the family is done, the family is linked with local authorities and other organs involved in the follow up of the child (***inshuti z' umuryango=friend of families, community health workers, representatives from the National Council for People with Disabilities (NCPD), Day Care, Early Childhood Development Centres, School, Health facilities, Hospital, etc).*** Once the child and family assessment and preparation have been completed, the family welcomes the child ensuring that his/her rights to enjoy the love of a family is guaranteed.

In case a child does not have a biological family, S/he is welcomed by an extended family and when this is not possible, the child is welcomed by Malayika Mulinzi. This is a very delicate process that requires professionalism, discernment and collaboration with various organs.

The first pilot project to reintegrate children with disability was done in Wikwiheba Mwana Institution located in Gatsibo district, Eastern Province. Above 80% of children were reintegrated in their biological families where they live in conditions that are better than the ones they experienced in the institution.

4. Can a child with disability enjoy a better life in a family?

If you compare the number of children with disabilities in institutions and families, you will find that the great number of children with disability live in families. Most of the children with disabilities are placed in institutions when their families are located near those institutions. Research has proven that children raised in families grow well in good health and have better social life compared to children raised in institutions. Moreover, reintegrated children enjoy a better life in families. In the end, they do not feel abandoned by their families.





5. Is it true that caring for a child with disabilities requires sufficient resources families can not afford?

Where there is will, there is a way or means. All families must have a plan for all the children including children with disabilities. Families that show the will but lack sufficient means must get the support from the government and its partners in order to be empowered in their efforts to care for the welfare of their children.

Families must support every child according to his/her needs, whether s/he has disability or not, every child in need of special care must get it because it is his/her right.

6. What kind of support does a parent who committed to foster a child with disability get to raise this child?

A parent who commits to foster a child with disability is someone who takes an outstanding heroic decision. This is an act of love shown by those who commit themselves and are recognized as compassionate people who have the will and the means, ready to offer rather than expecting to receive anything in return for their commitment. However, since a child with disability can need special equipment and special attention, the Government and its partners support the biological family or the Foster family based on an assessment of family resources and the needs of the child with disability. (For instance: to provide prothesis or assistive devices whenever needed, to facilitate the purchase of skin lotion using the community based health insurance (mutuelle de sante), to facilitate access to medical care in specialised hospitals, to renovate the house by enlarging the doors, to pave the way in order to facilitate the smooth passing of the wheel chair), to purchase a special bed or chair for children with disability, to advocate for the access of children with disability to Early Childhood Development Centres, primary schools and others.





7. Most of the children with disability get medical care support from Institutions, they take various drugs which are sometimes very expensive. Do families manage to provide medical care support to reintegrated children?

Children with disability have the right to medical care. The family that has welcomed a reintegrated child has the responsibility to take care of a child with disability including ensuring access to medical care using the community based health insurance or any other health insurance the family is using. Children with disability should get medical care from neighbouring health centres and hospitals or hospitals providing special services for people with disabilities. Whenever children with disability need specialised medical doctors who are not available in neighbouring hospitals, they are taken in other hospitals with specialised medical doctors and sufficient equipment.

Sometimes, the medical care of children with disabilities may be expensive and beyond the family resources. Local authorities and partners can advocate for the family until a child gets appropriate medical care.

8. Where will children with disabilities find specialised schools and medical care once they are reintegrated in families?

People say children get appropriate care, specialised medical care and quality education in institutions. However, many institutions are not officially recognized by the government as institutions providing medical or education services as many people think.

All schools are encouraged to provide inclusive education: early childhood development centres, nursery schools and primary schools, secondary schools and higher learning institutions. This goes hand in hand with planning user friendly facilities for people with disabilities such as special toilets, pathways, sign language and special assistance to children with disabilities.

The type of medical care children with disabilities need is available in various health centres and hospitals in the community. In some health centers and hospitals there are special services dedicated to people with disabilities such as kinesitherapy, mental health care, surgery etc. Therefore, a reintegrated child with disabilities will continue to receive the same medical care s/he got in the institution.





9. Will the parents be able to care for a reintegrated child with severe or complex disability and at the same time cater for other family responsibilities?

There are children with severe or complex disabilities who need special care and permanent medical care. In this case, all family members attend trainings where they learn how they can take turn in taking care of the child with disabilities (cleaning, counselling, massage, feeding, giving drugs, playing with, and socializing with family members). Experience has shown that when family members perform what they have learnt during the training, the child with disabilities improves her/his skills (feeding, turn on either side, socialisation, autonomy, speech, muscle coordination and body language).

10. How can you prepare a deaf or dumb child for re-integration? Do you really need to consider the child consent in that case?

Many people think that children with disabilities such as dumbness, deafness, mental disorders can not socialize and can not express their feelings. This is not true. The preparation of children with disabilities is done by experienced professionals through gestures and signs, braille text or other ways to stimulate their feelings. Moreover, during the preparation of the child and the family, there is collaboration with the caregivers and educators, their peers in the institution and their biological parents if they are present. The above-mentioned techniques are used to involve children in their reintegration.

11. Since the parent has been affected by the fact that s/he gave birth to a child with disability and decided to bring him/her in an institution in order to be relieved from the burden, is the reintegration not a new experience that is going to hurt the parent?

It is true that a parent who gave birth to a child with disability experiences deep sadness and a great sense of guilt. Though the separation with the family is perceived as a solution for the family, it hurts very much the family members (siblings, parents, extended family) but it affects even more the child who was separated from the rest of the family. The reintegration programme is a journey aiming at reunifying and healing the wounds hurting both the child and family. This must be done carefully and respectfully. Efforts are made to convince the family that a child with disability has the same rights to be raised in a family, considered as a place where his/her full growth will be accomplished taking into consideration his/her uniqueness.





12. Some children were taken in the institution after being abandoned by their parents. How sure are you if they will not abandon them again if you dare to reunify them?

Before reunifying a child with his/her family, a thorough assessment of the root causes of child abandonment is conducted. This is followed by a full assessment of the family which is ready to welcome the child with a focus on possible solutions to address the root causes of separation with his/her family. This is carried out by professionals, local authorities, the biological family and the extended family. When the root causes of separation with the family are still persisting, efforts are made to find another family for the abandoned child.

13. What can be done to prevent possible abuse against children with disabilities in the family?

It is true that children with disabilities are likely to experience all forms of abuse. Parents who have welcomed reintegrated children have understood deeply the rights of the children and their role in protecting them against any form of abuse and they commit to ensure children's safety. Moreover, there are various channels to engage the general public and dispel prejudices/myths around children with disabilities. Hence, they should not be discriminated or abused. The law punishes whoever abuses them. Some of these channels include media, parents' evening dialogue sessions (umugoroba w'ababyeyi), monthly community work (umuganda), meetings in the village (inteko y'abaturage), Friends of families (Inshuti z' Umuryango) and community health workers (abajyanama b'ubuzima).

In addition, professionals in collaboration with local authorities continue to monitor the living conditions of reintegrated children with disabilities.

14. Sometimes, conflict arises between couples when a child with disability is born in a family, the couple accuse each other of being the root cause of the disability. Is the conflict not going to reoccur if the child is reintegrated in the family?

Evidence has shown that in reality conflict are not caused by the child with disability as such. Conflict is caused by ignorance and mindset around disabilities; the causes of disabilities, the lack of experience on how to take care of a child with disabilities and other sources of conflicts.





Quite often, ignorance around the above-mentioned issues lead parents to believe that giving birth to a child with disability is a disaster, a curse, evil spirits. They end up concluding that the child will be useless for the family. Some of the biological or extended family members and even neighbours isolate and discriminate the child with disability. Hence, before the reintegration, family must attend a series of trainings to understand better the disabilities. When the family is not ready, another family is prepared to welcome the child.

15. Since many families may not manage to take care of children with profound disabilities, is it appropriate to keep them in residential institutions?

As far as caring for a child with any kind of disability is concerned, an institution should never be considered as a place that can replace a family. Nothing can replace a family, what is lacking in a family can not be found elsewhere, a family brings long lasting solutions. Before reintegrating a child, an assessment is carried out to evaluate the strengths and weaknesses of a family which is ready to welcome a child from an institution. Dialogue with the family is conducted by professionals and where necessary, support is provided to empower the family in their new commitment to cater for the child.

NB: When we mention a family, we do not limit ourselves to the biological or extended families. When the biological and extended families are not the best options, the foster family (Guardian Angels (Malayika Mulinzi) is contacted and prepared to welcome a child.

16. Who will care for children with disabilities who do not have biological or extended families when all the institutions will close?

In 2012, the Government of Rwanda adopted the Child Care Reform which stipulates that all children cared for in institutions be reintegrated in families. In 2013, the Government put in place the Let's Raise Children in Family programme in order to implement the Child Care Reform strategies. The first action was to reintegrate typical children from institutions into families. This programme is not meant for children who do not have disabilities only. It is intended also for children with disabilities because family life is the right of every child.





The Government Let's Raise Children in Family programme stipulates that every child who is abandoned by his/her parents should be catered for by the extended family. When efforts to identify the extended family are not successful, or they do not have sufficient resources and will to care for the child, the abandoned child with disabilities is raised by committed and trained Foster family (Guardians Angels-Malaika Mulinzi).

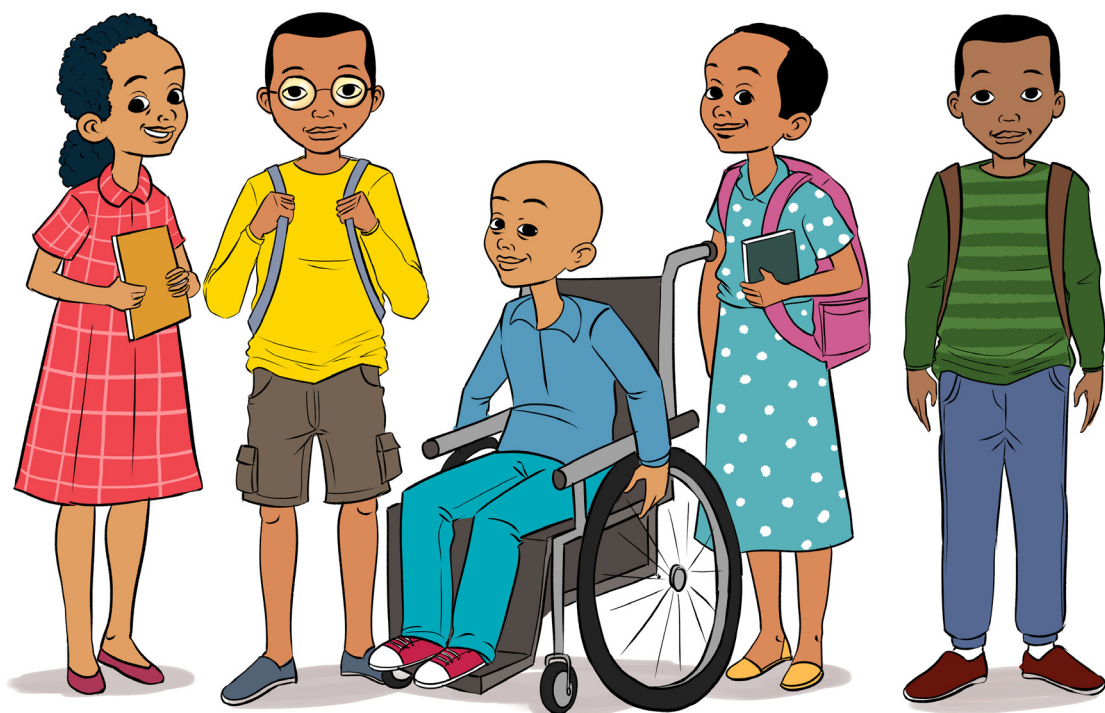
17. There are very few facilities or services for children with disabilities. Why are they not planned in advance before reintegrating these children?

No doubt, there are few services supporting people with disabilities. However, the reintegration does not prevent children with disabilities from receiving the services they need quite often. Even the residential institutions seek the same services within the community in order to support them. Through the National Council for People with Disabilities (NCPD) and its partners, the Government ensures people with disabilities enjoy their rights to services such as to pave ways that give better access for people with disabilities in schools, hospitals and offices. Children with disabilities can access to medical care using the community based health insurance (MUSA), inclusive education, special education, proximity health services at the health centers and specialised hospitals.

18. What will the residential institutions once they become empty after the reintegration of all the children with disabilities?

Residential institutions that catered for children with disabilities should be transformed into day care centers. This will increase the number of children supported around those institutions as well as the number of services provided to children with disabilities. They should continue to provide services to children with disabilities in the community including reintegrated children. The number of children supported around those institutions as well as the number of services provided to children with disabilities will increase. The services that can be provided include: inclusive education, basic health care such as kinesitherapy, production and distribution of prothesis or assistive devices, train parents on positive parenting and care for children with disabilities, inclusive early childhood development centres, support leisure activities through the games, fight against malnutrition, creation of Saving and Lending Groups etc.





Republic of Rwanda
Ministry of Local Government



NATIONAL COUNCIL FOR PERSONS
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