

Regional learning platform on care reform in Eastern and Southern Africa

CASE STUDY



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An integrated model to prevent family separation

for children living with disabilities in Rwanda

Introduction

Over the past decade, the Government of Rwanda has carried out extensive carereforms. With the support of UNICEF, the Government reintegrated the majority of children in residential care with their families, established foster care, and developed a professional and volunteer workforce with expertise in child protection, supporting vulnerable families and providing alternative care.¹ Much of this work has taken place under the auspices of the Tubarerere Mu Muryango (TMM) or Lets raise children in families programme.

Over the last five years, the focus of care reform has shifted towards children with disabilities, with a growing recognition of the importance of multi-sector support at the community level to enable children with disabilities to remain in their families. In conjunction with the TMM programme, a pilot project has been established in two districts, Huye and Bugesera. The pilot provides a comprehensive package of guidance, services and support through coordinated inputs from the child protection, education, social protection, health, nutrition, and water and sanitation sectors.

It is hoped that by demonstrating the value of this integrated model the Government will expand this approach across the country.

The pilot is a collaboration between the National Council for Persons with Disabilities (NCPD), the National Child Development Agency (NCDA), UNICEF Rwanda and the civil society organization called Chance for Childhood (CfC). The pilot has been generously funded by the Swiss National Committee of UNICEF, and the TMM Programme by USAID's Displaced Children and Orphans Fund.

In this short case study, we explain why this integrated model is important to prevent family separation, outline the key components of this approach, and provide some lessons learnt from the pilot. This case study is based on interviews with 13 policy makers and practitioners, two parents of children with disabilities, and one child with disabilities.

Why is it important to help children with disabilities stay in families?

As articulated by the Convention on the Rights of the Child² and the Guidelines for the Alternative Care of Children,³ the family is the natural environment for a child to grow-up in, and children should only be separated from their parents if it is in their best interests. These rights apply to all children,⁴ including those with disabilities, and the rights of children with disabilities to a family life is further enshrined in the Convention on the Rights of Persons with Disabilities. Maximum efforts must therefore be made to keep children with disabilities in families and to reintegrate those who have already been separated from their parents or other family caregivers.

Global evidence shows a lack of opportunity for bonds or attachments with caregivers means that institutional care hinders child development.⁵ In some cases, this harm can exacerbate disabilities.⁶ Policy makers and practitioners in Rwanda argue that growing up in families is vital for children with disabilities to feel loved, and to have a sense of belonging in families and communities. Enabling children with disabilities to reach their full potential is seen as not just beneficial for the child and their family, but for the whole of Rwandan society.

“The first thing when a child is born, they must be given love, and this love is given by parents as they grow up in the community.”

Disability mainstreaming officer

Huye District

“When they don't have rights in their families they feel neglected and hate themselves, like they aren't like other children.”

Vice Mayor in Charge of Social Affairs

Huye District

“We should all believe that having a lot of persons with disabilities who are not educated, who are not accessing the health care services they need like any other person is itself a burden. And disability is not in ability. If you all work together to address disability, we are addressing a very good cause, and we expect high returns in the future.”

Director General

Kabutare District Hospital

Before the start of the pilot, Chance for Childhood, mapped existing services and supports for children with disabilities through the TMM programme.⁷ This mapping, and interviews carried out for this case study, highlighted a range of reasons why families caring for children with disabilities need extra support to prevent placement into residential care. Children with disabilities often need additional daily care, including help with washing or using the toilet. Some children with disabilities, such as a cleft palate, struggle to eat and this can lead to malnutrition. Children with some disabilities have difficulties speaking or hearing and parents and caregivers often lack the skills to communicate with them. Parents sometimes feel that residential care providers have more time and skills to care for their children.

“She can't do anything for herself like going to a toilet or grabbing something to eat in case she's hungry, even going to school is a challenge because we have to take her there, so we have to do everything for her.”

Parent of a child with disabilities

Families caring for children with disabilities are often poorer than other households as parents or other caregivers have given up work to care for these children. They may also have to pay for extra health care or assistive devices for children. Parents often place children in residential care because they feel they cannot provide for them and the other children in the family.

Health care and rehabilitation for children with disabilities is often expensive and inaccessible in Rwanda. Treatment may only be available in hospitals far away from home. Assistive devices, such as wheelchairs or hearing aids cost too much for poor families to afford. Children with disabilities lack access to school for a range of reasons, including challenges getting to schools, inaccessible classrooms, inappropriate teaching aids, the cost of uniforms and books, discrimination by teachers or other students, and teachers lacking the skills to teach children with disabilities. Placing a child with disability in residential care is often seen as the only way to access health, social services, care, rehabilitation or education services.

“The challenges my child faces are that she is always sick, and the transport costs to take her to the hospital are a challenge.”

Parent of a child with disabilities

Both children with disabilities and their parents are stigmatised and discriminated against in families and communities and by service providers. Children with disabilities are seen as having lower value than other children and not worth the investment of the costs associated with bringing a child up. Parents and other caregivers may place children in residential care to avoid this stigma.

“Sometimes we are given names like a parent who gave birth to a ‘crippled’ child. They say ‘they are useless, they are not children like the others.’”

Parent of a child with disabilities

“People are still afraid and you find children are locked in houses because they have disabilities. They say that they aren’t supposed to be with others.”

Deputy Teacher

Mpare Primary School

“Some communities call them nicknames, often comparing them with broken pots or animals... When a child is born with a disability, the relative of their parents accuse them of bringing a curse to the family.”

Chance for Childhood staff member

“They say ‘we are raising a child who will not go to fetch water, to collect wood for you,’ they just see that she or he is lying down, so to many people they are the children who cannot do anything, who are not important for the family.”

Government official

“[Parent think] ‘if I take this child to the institution, I feel safe, I will be valued within the community and no one will ever exclude me or say bad words against me.’ So, stigma and discrimination are one of the key factors that may lead to the separation of children with disabilities and their families.”

Programme Manager

Chance for Childhood

Although some parents may feel relieved to have placed a child with disability in residential care, many feel a deep sense of loss, having made this decision with much difficulty.

“There's always that worry - ‘who is going to give my child the same level of love and protection that I give as the parent?’ and that alone sometimes makes it very difficult for a family to come to a decision on what the best care mechanism is for their child.”

UNICEF staff member

“I didn’t think of taking my child to these institutions that care for children with disabilities. I was emotional and I couldn’t let my child go.”

Parent of a child with disabilities

What is an integrated approach to working with children with disabilities?

An integrated approach involves working in a coordinated way across sectors to meet the needs of children with disabilities and their families. Integration happens at all levels, from national policies down to work with communities. It involves collaboration between national and local government institutions, United Nations (UN) agencies, and NGOs, Faith Based Organisations, Private Sector and Media. In Rwanda, the key sectors involved in this approach are child protection, social protection, education, health and nutrition, and water and sanitation. To fight stigma and discrimination, social and behaviour change strategies are utilised across these sectors.

Why is an integrated approach important for keeping children with disabilities in families?

The factors which lead to family separation for children with disabilities are multi-faceted and cannot be addressed by one sector alone. The challenges faced by children with disabilities and their families are often closely interrelated. For example, stigma affects lack of access to services. Meeting the daily care needs of children impacts on parents' ability to earn a living, which in turn means they cannot pay for health care or education. Addressing only one of these issues provides only a partial solution.

“Child Protection has been working in this field for a very long time. But clearly, we were not going to be able to keep children in families by promoting family care, working with families, parent groups and all that, if the nearest school does not accommodate children with disabilities, if the health centre does not accommodate children with disabilities.”

UNICEF staff member

There are an estimated 46,869⁸ children with disabilities in Rwanda aged five to eighteen years old. The large number of children with disabilities, and limited resources available for their care, mean that it is vital to find efficient ways to work with this group. An integrated approach allows the pooling of resources and expertise.

This approach also promotes service delivery in a common location and referrals between services, making it easier for parents and caregivers to access services. Government officials in Rwanda have noted how joint interventions can create a stronger movement for promoting the rights of children with disabilities.

“If we all unite and show [children with disabilities] we care, they also learn to believe in themselves and learn that they can live like any other person.”

Vice Mayor, Social Affairs

Huye District

What are the key components of an integrated approach?

Policies, strategies and planning

In Rwanda, an integrated approach has been formalised through the National Policy of Persons with Disabilities 2021,⁹ and in various sector-specific strategies which reference disability.¹⁰ This policy reform is seen to be vital for achieving country-wide change.

“The intention from the beginning is a national program. So that is also something that is quite key because when you go to government, it's best not to go with scattered projects, but with coherent interventions and programs that build towards something bigger that you can also leverage public finance towards.”

UNICEF staff member

Within UNICEF, a joint theory of change and concept note has been developed involving the various sections working with children with disabilities. This document articulates common objectives and outlines how each section will contribute to these goals. It has been used as basis for joint programme plans, with this joint planning most successful when carried out from the very beginning of interventions.

Coordination mechanisms

Coordination is vital for a fully integrated approach. Coordination enables smoother joint work, improves referral mechanisms and promotes accountability as it allows sectors to monitor each other's progress. Two different types of coordination mechanisms have been used to support the pilot. First, disability has been integrated into existing coordination mechanism for care reforms, such as the Child Protection Working Group.

Second, a national and sub-national coordination structure relating specifically to disability has been activated, starting with the two pilot districts. These coordination mechanisms involve NCDA, NCPD, and a range of government agencies and NGOs. They exist at the national, district and community levels, with meetings generally held on a quarterly basis. In the two pilot districts, meetings have been coordinated by NCPD with the support of Chance for Childhood. In the second phase of the pilot, efforts will be made to handover full responsibility for coordination to government.

Institutional and workforce capacity building

Efforts have been made to build the capacity of the government agencies involved in the pilot. Staff working at the national level have been trained on the rights of children with disabilities and how they can contribute to meeting these rights. Managers have been supported to develop more integrated approaches in their planning. Frontline staff in the two districts, such as doctors, social workers and teachers, have received training on the skills and knowledge they need better support children with disabilities.

In the child protection sector, particular attention has been paid to building the capacity of the Inshuti z'Umuryango (IZU – Friends of the Family), to work with children with disabilities and their families. These community volunteers play a vital role in identifying children with disabilities, helping families come to terms with a diagnosis of disability, providing referrals to services, and giving guidance on how to care for these children.

“You find women are the ones taking care of children alone, taking them to hospitals, schools, and men don't even care. They are just drinking alcohol, and this results in misunderstandings in families. Some parents blame each other as the cause of them producing a child with disabilities. This is where IZU come in because they were trained to solve family disputes.”

Government Social worker

Identification and diagnosis of children with disabilities

Early diagnosis of disability is important for effective treatment and rehabilitation. Doctors, nurses and midwives in the two districts have been trained to spot disabilities in the womb and from birth and to make the necessary referrals. IZU and community health volunteers have also been trained to identify children with possible disabilities and refer them to health care professionals for diagnosis. Doctors involved in enhanced screening through this programme report dramatic results. For example, children with hearing loss being treated through the simple removal of ear wax.

The stigma associated with disability also means that identification includes finding children that have been hidden in homes by families. With their knowledge of communities and strong relationships with vulnerable families, the IZU play a vital role here.

Case management and referral mechanisms

The pilot coincided with the roll out of a national case management system, providing an opportunity to ensure that case management guidance is inclusive. Some case management tools have been adjusted to include reference to the needs of children with disabilities. Specific tools have also been developed for work with children with disabilities.

Tools have been adapted to reflect the multi-sectoral approach. For example, family and child assessments used to be completed by a social worker or psychologist. Now, education and health professionals are also involved in this process. As with all case management in Rwanda, the IZU contribute to case management processes with children with disabilities. IZU monitor children with disabilities and their families closely and flag any concerns they are unable to address to district

level Child Protection and Welfare Officers. This is done using a text message-based system. As well as these referrals between the community and district level social services, an integrated approach requires strong referral mechanisms between social workers, and the health, education and social protection sectors.

Service provision

To address the factors that lead to children with disabilities being separated from their families, it is important to ensure they can access the following services.

1 **Inclusive education:** Previously, children with disabilities were either largely not attending school or taught in a small number of special schools, often involving placement in residential care. The integrated model encourages inclusive education, allowing children with disabilities the opportunity to attend mainstream schools and remain part of their families and communities. Inclusive education requires:

- adjustments to school infrastructure to make schools more accessible, providing appropriate toilet facilities,
- giving teachers the skills needed to communicate with and teach children with disabilities,
- encouraging parents to recognise the potential of children with disabilities and send them to school,
- the provision of assistive devices to make it easier for children to travel to school or consult teachers,
- teachers conducting home visits to any children who regularly miss school,
- building the confidence of children with disabilities and belief that they can do well in school, and
- challenging discrimination by teachers and other students.

“We used to be isolated at home, not being able to bring her to other children in public. It used to make us ashamed because of how the child looks different from other kids. But then came the organisation called Chance for Childhood who encouraged us to join cooperatives and trained us and taught us how our children with disabilities are as normal as other children and told us to bring them to school ...and associate with other children, to see that they are also children. That's how I brought her to this school.”

Parent who enrolled her daughter at Mpare Primary

School

2 **Health and nutrition.** As part of the integrated model, children with disabilities are monitored by community health volunteers. These volunteers identify any concerns around health or nutrition and make referrals to local health care providers. Where possible, doctors organise clinics for children with disabilities in communities so that they don't have to travel far. Community health volunteers follow-up after treatment and report any issues back to doctors. Where families are reluctant to seek treatment from doctors, community health volunteers and IZU work together to encourage them to get help.

“There is a family that had a child with a leg disease and believed that the child had been bewitched. We informed them how it can only be treated in hospitals and not using traditional medicine. They went to a hospital where they spent, like, three months and the leg was operated on and treated. The child was given a walking stick and now this child is in primary six. He is now 16 years old and growing up.”

IZU

3 Community based physiotherapy and assistive devices.

The integrated model aims to make physiotherapy and assistive devices more accessible to children with disabilities. One physiotherapist in each district runs regular clinics in communities and teaches parents simple physiotherapy exercises they can do at home with their children. This is critical in ensuring that children with disabilities receive support in and closer to their homes. So far 174 community rehabilitation sites have been established in all or most of the cells in the two districts, reducing the time and costs associated with a visit to the physiotherapist. Physiotherapists are seeing dramatic results. For example, in one of the two districts included in the programme, 32 children who could not move independently can now walk to school without support. Others can now sit unaided or feed themselves for the first time. More affordable wheelchairs and other assistive devices have been developed, and the government have now agreed to allow parents to use their health insurance to pay for these devices. Parents are also taught to make adapted chairs and toys for their children.

“Yes, there are people who help me with joint stretches, and it has helped with the pain in my joints. The pain is not as much as it used to be.”

Girl with disability

4 Water and sanitation. The integrated model has worked to improve water supply for families caring for children with disabilities. These households need clean water close to home as caring for a child with disability is time consuming, leaving less time free to fetch water. Children with disabilities may also need more water than other children. For example, if they use diapers and need to be washed more often. The programme also supplied accessible toilets and washing facilities in communities and schools.

5 Social protection. IZU, community health volunteers and government Social Welfare Officers have been trained to identify families that are struggling financially. Referrals are then made to government and NGO social protection schemes.

Rwanda has a new government run Disability Grant which supports children with severe disabilities. So far, around 842 children in the two districts have been identified as eligible. These families are receiving monthly cash grant ranging between RWF 5,000-12,500 (USD \$4-10) depending on whether they are already receiving other government grants. The impacts of the Disability Grant on child and family wellbeing will be closely monitored and it is hoped that the grant will be expanded to the rest of the country in the future. In addition to this grant, families may also be eligible for other government run social protection schemes and NGO livelihoods initiatives. Parents groups set up as part of the TMM programme run a revolving savings and loans scheme. Some parents have formed cooperatives and have set up small businesses together, such as chicken rearing and egg productive. Money is often used to pay for medical insurance, with parents reporting a rise in the number of insured families in their groups.

“My child was unable to attend school. I came [to the group] and they give me a loan and I pay school fees. I slowly save and pay an interest rate of 5 per cent based on the money I took.... We plant and harvest together and later share the profits.”

Parent

6 Parenting support. Parenting support groups have been established across the two districts included in the pilot. In one district alone there are 3,142 parents in 76 support groups, with groups ranging in size from 21 to 56 parents. Parents meet regularly to share the challenges they face and receive training on how to care for and support their children with disabilities. They are encouraged to better understand the needs of these children, to value them and recognise their potential.

“We help them to find solutions amongst themselves we help them love their children.”

Vice Mayor, Social Affairs

Huye District

“I didn’t know if there was any other parent with a child who has disability. I always thought I was alone. ... When you overcome being lonely, everything is possible.”

Parent of child with disabilities

“We have strong faith that our children have a bright future ahead like other parents believe that their children will be useful to them. That’s what we feel about our children with disabilities.”

Parent of child with disabilities

“Based on the good things I have seen in associations; I would advise my fellow parents to stop being lonely and unite together and form associations. Because you talk to each other and leave happy and learn ideas on how to take care of a child with disability. If there is something you didn’t know, you learn it from your fellow parent.”

Parent of child with disabilities

7 Protecting children with disabilities from violence and abuse. Owing to discrimination, physical vulnerability and difficulties communicating, children with disabilities in Rwanda are more likely to experience violence and abuse than other children. The TMM programmes addresses this risk by:

- teaching parents to take extra care for children with disabilities,
- training IZU to monitor these children and raise concerns with Child Protection and Welfare Officers,
- challenging stigma and discrimination in communities, and
- raising awareness that violence against all children, including those with disabilities, is punishable by law.

“We follow them [children with disabilities] closely because they need more attention than other children. This encourages us to go into their family to find out if these children are treated like other kids. Are there factors that may lead to mistreatment in these families? We teach parents how to treat these children and train them and stop calling them the nicknames that we had in the past.”

IZU

Addressing stigma and discrimination

The programme seeks to address stigma and discrimination in families, schools, health clinics and communities. Efforts have been made to raise awareness that children with disabilities have value and rights like any other child. Families have been sensitised as part of parenting support groups. Meetings have been held with service providers and teachers have worked with students to respond to any bullying of children with disabilities. Wider communities have also been educated by IZU and Community Health Volunteers using radio talk shows, community events and social media campaigns.

“Some families experience conflict because they have a child with a disability, with fathers blaming mothers. As an IZU, we teach them that it is no one’s fault that the child has a disability and that both parents share the responsibility of caring for their child.”

IZU

“Those who could not take their children to the churches or to the public gatherings are now comfortable to take their children there. So, it is an improvement, and this impact is there in the community.”

Parent Liaison Officer

Chance for Childhood

What lessons have been learnt in applying an integrated approach in Rwanda?

1. Government commitment is key for sustainability.

“I can advise them to make a commitment, but commitment supported by the government. Because when it is led by partners, ...the children can be left without having services or continued support.”

Government programme manager

2. Joint plans, monitoring and evaluation frameworks and training, and a commitment to working in an integrated way are vital for moving away from more siloed approaches.

“We get so much absorbed and involved in our own tracks of work that we just hit the ground and run and go and forget that we actually need our education colleagues.... There's always sector fights when it comes to pulling resources to my own sector and the others to their own sector, which sometimes obliterates the opportunity that we have to actually share the little resources.”

UNICEF staff member

3. Begin with research and develop context specific integrated programmes based on the needs of each community.

“Another advice I can give is focusing on what the community needs. Instead of preparing a long project for them, meet them and ask them what they need.”

Physiotherapist

4. It is valuable to start with pilot districts, but for models to be replicated or scaled- up, they must first be documented.

“So often we document the lessons, we document the good practices, but we rarely document a model. And this is one of the things that we are now working on to ensure that we are able to tell what is the package? What needs to happen in education? What needs to happen in health? What needs to happen in water and sanitation? For us to be able to have an integrated model. So, to have like a package that you can put there and someone can open like a manual.”

UNICEF staff member

5. It is important to estimate the costs of integrated models.

“We will also look at the cost implications of delivering such a package. And again, the cost implications will differ, by context, by district So, we are looking at all those and doing a proper cost analysis to ensure that we are able to tell how much government needs to put in to be able to implement such a model.”

UNICEF staff member

6. Change begins within families. It is vital to build rapport with parents and get them to appreciate and value their children with disabilities. They then become effective advocates for their children.

“The parents are the best, the key partner. They are the primary caregiver for their children. When again they love their children, with their commitment, their support, things are moving very well.”

Government programme manager

“You learn how to ask parents questions, how to make them friends first so that you communicate easily and make yourself as a friend, like a neighbour.”

IZU

7. Community volunteers play a vital role in multiple aspects of case management, service provision, and in reducing stigma and discrimination against children with disabilities.

Conclusions

Like other children, children with disabilities have a right to remain in their families, providing it is in their best interests. Placing these children in institutional care denies them a crucial attachment with a consistent caregiver, a loss that can exacerbate their disabilities. Children with disabilities in Rwanda are placed at risk of separation by a range of factors. Parents may believe that their needs are better met by residential care providers. Families are often poor and lack of access to affordable assistive devices and rehabilitation, education and health services. Stigma and discrimination also push children apart from families.

Responding effectively to these multiple risk factors requires an integrated approach. This involves coordinated work across child protection, social protection, education, health and nutrition, and water and sanitation sectors. An integrated approach allows the pooling of resources and expertise, enables easier referrals between services and promotes a joint advocacy for the rights of children with disabilities.

An integrated approach requires joint strategies and planning, and collaboration and coordination mechanisms at the national and local levels. Staff working in each sector must be trained on disability rights, how to identify a child with disabilities, and how to work in an integrated manner. Those in the child protection and health sectors must work together to find and diagnose children with disabilities, overcoming stigma which sees these children confined to homes.

Case management must be adjusted to reflect the specific needs of children with disabilities and to promote cross-sector assessment and referrals. Children with disabilities must be offered a range of services including inclusive education, health and nutrition, community-based physiotherapy, affordable assistive devices and support with water and sanitation. Families should be able to access social protection schemes and parenting supports, with a strong emphasis on mutual support groups.

Children with disabilities must be protected from violence and abuse, and steps must be taken to avoid stigma and discrimination. Lessons learnt from the application of an integrated approach in Rwanda imply that success hinges on government commitment, joint planning, training and monitoring and evaluation, and developing context specific, costed and well documented models. Parents, caregivers and community volunteers are key to successful support for children with disabilities.

Acronyms

IZU	Inshuti z'Umuryango (Friends of the family)
NCDA	National Child Development Agency
NCPD	National Council of Persons with Disabilities
NGO	Non-governmental Organisation
RWF	Rwandan Franc
TMM	Tubarerere Mu Muryango programme (Lets raise children in families)
UN	United Nations
USD	United States Dollars

Endnotes

1 UNICEF (2021) *Care reform in Rwanda. A virtual study tour*

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