“Tubarerere mu Muryango” Programme
(Let’s raise children in families)

MY CHILD: PARENTS INFORMATION SHEETS ON CHILD DISABILITY

“Tubarerere mu Muryango” Programme
(Let’s raise children in families)

MY CHILD: PARENTS INFORMATION SHEETS ON CHILD DISABILITY

This document is a property of the National Child development Agency. It can be used by any interested person in accordance to the instructions provided. However, the owner reserves the rights to make any change to the document without a written content.
How to use this resource

This document is for parents and caregivers on child disability.

The sharing of the information contained in the guide should be facilitated by a person with some knowledge of disability. For example, the District Child Protection and Welfare Officer, Inshuti z’Umuryango (IZU)/Friends of the Family, Community Health Workers, the Disability Mainstreaming Officer, and other Community-based Inclusive Development stakeholders etc.

The facilitator can gather a group of parents and caregivers at regular times and go through the chapters at the most suitable place for them. Or the facilitator can use the guide with individual families during regular household visits.

The sheets are designed as a standing flipboard with pictures on one side facing outwards towards the parent and caregiver participants, and with the instructions facing in towards the facilitator.

With the pictures facing towards the parents the facilitator should point to each picture in turn and describe what is happening, prompted by the text on the side facing them.

There are ten (10) chapters to work through.

• **Chapter One** is a short introduction on what disability is
• **Chapter Two** talks about the rights of children with disabilities
• **Chapter Three** describes the types and effects of disability
• **Chapter Four** describes child developmental milestones
• **Chapter Five** is about how to detect early if your child has a developmental delay or a disability (sometimes called early detection)
• **Chapter Six** is about how you can support your child when you notice they might have a delay or disability (sometimes called early intervention)
• **Chapter Seven** gives some ideas for communicating with a child who has a disability
• **Chapter Eight** is about how parents and caregivers of children with disabilities can support each other
• **Chapter Nine** helps parents and caregivers think about how they can involve their child with a disability in the usual community activities
• **Chapter Ten** helps parents and caregivers to think about the different types of services they can access in their own area if they need help for their child
• **Picture 1.1:** Disability is the complex relationship between the mind, the body, and the environment in which a child lives.

• **Picture 1.2:** Disability can be present at birth or acquired later, and can be related to genetic factors, physical trauma or other unknown causes.

• **Picture 1.3:** If you think that your child might have a disability you should tell someone straight away so you can get all the help you need. You can contact the IZU or Community Health Worker in your village or visit the local health centre or your district hospital.

• **Picture 1.4:** Sometimes people think that disability is an illness. This is called the medical model of disability. It only considers what people assume is wrong with a child and how it can be fixed. Adults with disabilities have told us this is not the correct way to think.

• **Picture 1.5:** All children are unique, some learn more quickly than others, we think that children are “disabled” by barriers in society. This is called the social model of disability. Barriers can be physical, like buildings not having accessible entrances or toilets.

• **Picture 1.6:** Barriers can be people’s negative attitudes.
CHAPTER 2

Rights of children with disabilities
• A right is something you are allowed to do. The government and all the public services must respect your rights which are guaranteed in the law. No one can take them away.

• Some rights are described in international law which the Government of Rwanda has agreed to uphold
• By signing the United Nations Convention on the Rights of the Child document in 1991 (also called the UNCRC) the Government of Rwanda agree that all children under the age of 18 have the:

  - **Picture 2.1:** Right to life, survival and development; (this includes the right to go to school)
  - **Picture 2.2:** Right to non-discrimination; (this means children with disabilities have the same rights as all children);
  - **Picture 2.3:** Right to express their views freely
  - **Picture 2.4:** Right to have a child’s best interests taken as a primary consideration in all matters affecting them.
  - **Picture 2.5:** Right protection from violence, abuse, exploitation and neglect

• In 2008 the Government of Rwanda also signed the United Nations Convention on the Rights of Persons with Disabilities (also called the UNCRPD). By signing this they agreed that children with disabilities have all the same rights as all other children.

  - **Picture 2.6:** The Law of Rwanda No 01/2007 of the 20/01/2007 relating to the protection of people with disabilities in general says that a disabled person has the right to live in the family in the same conditions as others.
CHAPTER 3

Types and effects of disability

3.1
3.2
3.3
3.4
3.5
3.6
A disability can affect children in different ways, even when one child has the same type of disability as another person. Some children can have more than one type of disability. There are many types of disabilities, such as those that affect a child’s:

<table>
<thead>
<tr>
<th>Disabilities can involve a child’s:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Motor skills (the movement of muscles the way we want them to)</td>
</tr>
<tr>
<td>• Sensory ability (sight, hearing, smell, taste, touch, balance and body awareness)</td>
</tr>
<tr>
<td>• Behavioural skills (manage emotions, build healthy relationships, and show empathy and understanding)</td>
</tr>
<tr>
<td>• Intellectual functioning (when the thinking and learning process is not as quick as usual)</td>
</tr>
<tr>
<td>• Communication skills (hearing and understanding and expressing)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Maze bikamugiraho ingaruka mu bikorwa bikuriira:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Picture 3.1: Sit, crawl or walk or move around by themselves</td>
</tr>
<tr>
<td>Picture 3.2: Hold or manipulate objects; Use the toilet, dress or feed themselves appropriately</td>
</tr>
<tr>
<td>Picture 3.3: Learn from their environment</td>
</tr>
<tr>
<td>Picture 3.4: Manage their emotions and demonstrate age-appropriate behaviour</td>
</tr>
<tr>
<td>Picture 3.5: Learn, understand and apply complex information</td>
</tr>
<tr>
<td>Picture 3.6: Use words to communicate, express their thoughts and feelings or to understand others, speak clearly and be understood, Understand simple directions.</td>
</tr>
</tbody>
</table>
Basics of Child Development

CHAPTER 4

4.1

4.2

4.3

4.4

4.5

4.6
• Picture 4.1: From birth to age three is a critical period of brain development, and it is very important to encourage and stimulate all children as much as possible during this time. The brain develops and grows with every touch, movement and new sensation; the more experiences a child has during this important period, the better their brain development.

• Picture 4.2: Every child develops at different rates. But there are some typical stages by which we can expect a child to have begun to do the same things as other children of a similar age. These are called developmental milestones.

Typical development timeline for infants from birth to 2 years:

• Picture 4.3.a: 1 month old: Loves looking at faces and begins to recognize family members/primary caregiver, may be startled if they hear loud and sudden noises

• Picture 4.3.b: 2 months old: Can hold head up, begins to push up when lying on tummy, begins to smile at people, pays attention to faces, begins to act bored (cries, is fussy) if the activity doesn’t change

• Picture 4.4.a: 4 months old: Holds head steady, unsupported, uses hands and eyes together, smiles spontaneously, begins to babble, cries in different ways to show hunger, pain, or being tired

• Picture 4.4.b: 6 months old: Begins to sit without support and pass things from one hand to the other

• Picture 4.5.a: 9 months old: Stands-up holding on, may be afraid of strangers, has favourite toys

• Picture 4.5.b: 1 year old: Copies gestures, tries to say words you say, is shy or nervous with strangers

• Picture 4.6.a: 18 months old: May walk up steps and run, knows what ordinary things are

• Picture 4.6.b: 2 years old: Begins to sort shapes and colours, kicks a ball, gets excited when with other children.

As your child becomes older think about other children of a similar age in your family or in your community and what they can typically do. If you are worried that your child is not reaching their developmental milestones you can talk to your IZU or Community Health Worker, or to your nearest health center.
How to detect early if your child has a developmental delay or disability?
How to detect early if your child has a developmental delay or disability?

- **Picture 5.1**: No one knows your child better than you do. As a parent, you know their cries, their giggles, and their moods. Your child also knows your voice, your smell, and your touch—even from birth! You are and will be the first person to notice if your child isn’t meeting their developmental milestones. It is very important you do full body inspections and watch carefully your child during activities of daily living. By this, you will be able to notice anything that might restrict typical development of your child.

- **Picture 5.2**: Some children will present physical impairments which you can see and inspect. For some others, they have hidden impairment that you cannot see or inspect. Always check if your child has any trouble in body functioning in movement and posture, eating, sleeping, understanding, expressing, or communicating.

- **Picture 5.3**: In case your child has a developmental delay, there is a need for access to early intervention as soon as possible to ensure that no time is lost. If you suspect your child has a developmental delay or disability, ask for advice from your IZU, CHW or a nearest health center. You may even seek help from professionals at the hospital.

- **Picture 5.4**: Children who are affected by neurodevelopmental conditions such as cerebral palsy, might present motor difficulties as well. They might present flaccid or spastic muscles, difficulties coordinating the body, difficulties eating/chewing, difficulties seeing, difficulties controlling behaviour, etc.

- **Picture 5.5**: There is no cure for disability. However, parents, caregivers, and professionals can play a vital role by providing therapeutic interventions to prevent severe complications and improve functional independence of the child. This intervention can be done in family and community settings.

- **Picture 5.6**: Therapeutic interventions are also done within clinical setting by rehabilitation professionals such as hospitals and rehabilitation centers.
How you can support when you notice the child might have a delay or disability?
As a parent, always keep in mind that no one knows your child better than you do. You are and will be the first person to notice if your child isn’t meeting their developmental milestones. Always remember that children learn through play. Engage your child in early stimulation and development activities. So, try to turn every activity you do with a child into play or a game.

Engage your child in early stimulation activities:

- **Picture 6.1**: To help the child lift and control her head (and use her eyes and ears)
- **Picture 6.2**: To encourage rolling and twisting
- **Picture 6.3**: To help develop gripping, reaching, and hand-eye coordination
- **Picture 6.4**: To improve body control, balance, and sitting
- **Picture 6.5**: To improve standing, walking, and balance
- **Picture 6.6**: To improve communication and speech

Always remember that play is more important than toys. Almost anything-pots, flowers, sandals, fruit, keys, an old horseshoe-can be used as a toy, if it is used in play. However, you must ensure that toys are clean and safe for the child’s safety.
Communicating with a child who has a disability
When talking to a child with a disability remember the “Golden Rule”, remember that you are interacting with a child and keep the same tone and language as you would with any child of a similar age.

- **Picture 7.1** Children develop language when all their senses are stimulated – touch, sight, hearing, smell and taste. Play with your child, make sure you are in their line of sight when you speak with them, tell your child what you are doing, sing. Ask your child questions and give them time to answer. Do not try to “make the child learn” but give them lots of learning opportunities. Ask questions that need words for answers, not just yes and no. For example, “Do you want the blue one or the red one?” and “Who is coming on the path?” and “Where is the plate?”

- **Picture 7.2** When the child has difficulty pronouncing words do not correct them. Instead repeat the words correctly and clearly showing that you understand.

- **Picture 7.3**: To get the child used to language, explain everything you do with him. Use clear, simple words – the same ones each time. Name toys, objects, body parts. Repeat often.

- **Picture 7.4** Understanding what a person is saying depends not only on hearing but also on watching lips, facial expression and other gestures that a person makes when talking. Make sure that the child can see you when you are speaking to them and that you are both on the same level. Try not to speak about the child as if they are not in the room. Many people make the mistake of talking about a child with a disability as if the child cannot hear or understand what is being said. But this can hurt their feelings, (especially if the person talking is saying negative things about the child), in the same way it can for all children.

- **Picture 7.5** Be empathetic, warm and genuine when talking to a child with a disability and appreciate that they have a valuable perspective too.

- **Picture 7.6**: If a child is slow to begin speaking it is important to have their hearing checked. Even if the child hears some noises, they may not hear well enough to understand speech.
How parents and caregivers of children with disabilities can support each other?

CHAPTER 8

8.1

8.2

8.3

8.4

8.5

8.6
• Parents and caregivers who have similar experiences can sometimes form informal groups to discuss the problems and challenges they face, to support each other and to celebrate and share their children’s progress.

• There is no blueprint for a perfect group and every group will be different. As mothers and fathers, aunts and uncles, grandparents, or siblings of a child with a disability it is important to have somewhere to share your experience with other people in your community who might be having the same challenges. Each person will have a different amount of time to give to this. It is important that fathers, uncles, grandfathers, and brothers join in too.

• A good Parent Support Group should be:
  - **Picture 8.1:** A welcoming and inclusive group
  - **Picture 8.2:** A group that meets regularly
  - **Picture 8.3:** A place where you can feel safe to talk about your feelings and discuss the challenges you might be facing, knowing that the conversation is confidential
  - **Picture 8.4:** A space where you can share ideas and find out more information
  - **Picture 8.5:** A group where members are interested in the healthy development of their children
  - **Picture 8.6:** A group where members support and look after each other

Try and find out if there is a self-help group in your own village, or a nearby village or cell for parents and caregivers of children with disabilities. This is different from a savings group because its main purpose is about mutual psychosocial support, not about finances. Of course, if the self-help group becomes well established, they may want to include a savings component at some point in the future. You can ask your IZU or Community Health Worker if they know about any support groups, or other parents of children with disabilities who might like to join a group with you.
Including children with disabilities in the community
A child with disability should be considered as a child first and treated with the same kindness and respect as any other child in the community. All children grow-up and learn from their experiences and just like all children of the same age, children with disabilities need to interact with their peers, neighbours, play with other children and discover a way of living and learning in the community. Mothers, fathers and caregivers can help children to interact with their community.

- **Picture 9.1:** Ask a neighbour, a friend or a family member to take care of your child in case you are away from home. Do not leave your child locked inside the home by themselves. This is not safe and can be frightening for the child.

- **Picture 9.2:** Don’t feel ashamed to go out in your village with your child. Take a walk with the child, you may go together in community meetings and other gatherings in your village.

- **Picture 9.3:** Attend religious ceremonies with your child. Don’t be pulled down by false beliefs in your community. Be confident; you have not done anything wrong to have a child with disability.

- **Picture 9.4:** When you visit your friends and neighbours bring your child with you. This will help them to get to know your child and to love them and appreciate them just as you do. Over time they will become good supporters for you and will help to change other people’s negative attitudes and beliefs. Encourage and teach other children to play with your child with disability. This will help to build an inclusive community in the future.

- **Picture 9.5:** Make sure to take your child to playgroups, to Early Childhood Development centre, to school, to the health centre, and to any special services which are available. This creates opportunities for your child to grow and develop and encourages other people in the community to think about including your child when more services become available.

- **Picture 8.6:** Make sure to involve your child in celebrations at home, and to participate in the social events in your village and community.
Some of the services in your area to help children with a disability
### Families of CWDs, IZU, CHWs
**Key services:**
- Screening
- Early child’s support
- Referrals
- Monitoring child growth
- Participation in community services

### Home, community and center based ECD centers
**Key services:**
- Inclusive Early stimulation, and play
- Positive parenting
- Nutrition
- WASH
- Child protection

### Health center
**Key services:**
- Consultations and referral to hospital or other service providers in accordance to the needs
- Pieces of advice and counseling

### Primary schools
**Key services:**
- Inclusive education services
- Assessment and placement of learners
- Awareness raising on inclusion among the school community
- Inclusive and/or special sports

### CBID programs
**Key services:**
- Parents’ Self-help groups
- Trainings to parents
- Psychosocial support
- Home based therapeutic activities
- Income generating activities

### Local government/cell authority
**Key services:**
- Social protection program services (VUP, Girinka, Direct support etc)
- Legal and medical aid/support to the victims of violence
- Community mobilization

### SACCO /BDF
**Key services:**
- Financial assistance to get loans for women and youth
- Micro credits

### District hospitals
**Key services:**
- Professional assessment
- Specialized rehabilitation services (physiotherapy, Occupational therapy, mental health, Assistive devices )
- Referrals

### NGOs and FBOs,
**Key services:**
- Pieces of advice and counselling for families
- Support small projects of the parents
- May provide Community based rehabilitation services
- Training parents and caregivers on how they can support their children with disabilities