



TUWALINDE

A Guide for Fathers'
of Children with
Disabilities



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Hello Fathers,

Welcome to the "Tuwalinde Guide for Fathers of Children with Disabilities." Although mothers are generally more involved with their child's direct care, a father's participation in the care of a child with a disability is linked to better child psychological health compared with families with non-participating fathers. This guide will help you understand things that will support your children in growing in a healthy and safe environment and will help you practice ways of caring, supporting, and protecting them.

To benefit from the information provided, you are encouraged to read and put the knowledge into practice. When you are not sure, always reach out to others or The Action Foundation for further help.

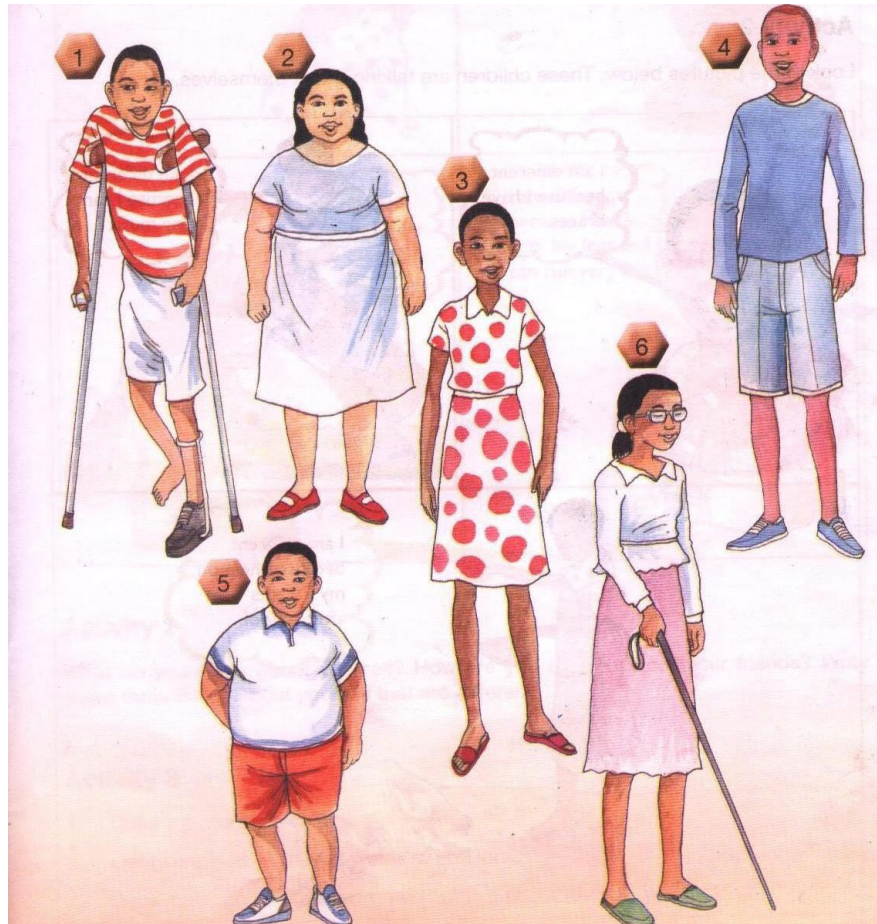
Enjoy!

A handwritten signature in black ink that reads "Maria Omare". The script is fluid and cursive, with the first letter 'M' being particularly large and stylized.

Maria Omare
Executive Director
The Action Foundation

I. EVERYONE MATTERS

Look at the following pictures of some boys and girls. What is different about each one of them?



REMEMBER

Everyone is different. Despite our diversity, everyone is unique because there is no one else in the world similar to another. Children with disabilities (CWDs) often have difficulty undertaking daily living activities due to the listed challenges. Regardless of their situation, they can contribute to society if they grow up in a nurturing environment. Every child with a disability has strengths. These may be in doing artwork, in their personality, or their motor skills. It's essential for us to focus on what children can do, their abilities, rather than their disability. We can use children's abilities to assist the areas where they have the most challenges.

II. UNDERSTANDING DISABILITY

As fathers, it is crucial to understand disability and how to address emerging issues around it. In doing so, we must differentiate between **impairment** and disability. Impairment means a long-term problem with the body or how the body works or structure (missing parts). At the same time, **disability** is a limitation imposed on impaired persons by attitudinal, institutional, or environmental barriers, making them unable to participate in societal activities meaningfully. There are several types of disabilities broadly categorized as follows;

There are several types of disabilities broadly categorized as follows;

- **Physical impairment;** affects a person's body movement and/or appearance.
- **Sensory impairment** - affects a person's sight, hearing, or speech.
- **Intellectual disability;** persons with significantly low intellectual functioning or reasoning below an average person of the same age (peers) and also lacks skills in adaptive behavior around everyday living tasks
- **Learning Disabilities;** persons do not have a problem with intelligence but cannot learn in the same way as their peers
- **Multiple Disabilities** – a child who has more than one impairment.



Several myths and misconceptions exist in many communities about the causes of disability. This occurs due to a lack of knowledge on disability. Examples include;

- It is a curse
- It is bad luck or bad omen
- It is contagious
- It is as a result of witch craft
- It originates only from the mother

What other myths and misconceptions can you identify in your community or culture?

The actual or established causes of disabilities in children vary. Some are biological (genetic abnormality, exposure to drugs and toxins such as alcohol, nicotine during pregnancy, premature birth, and difficulties during childbirth). Others are caused by the environment children live in, such as chronic abuse, severe neglect, childhood diseases, accidents, parental depression, or alcoholism. Socio-economic factors like poverty are also related to the development of mental problems.

Parents can take several measures to prevent disabilities in children. These could include;

Prevention during pregnancy;

- Avoiding unnecessary drugs and medications during pregnancy can potentially cause severe defects in an unborn child.
- Avoid drugs like narcotics and alcohol during pregnancy and breastfeeding.
- Avoid sexual contact with a person having venereal disease.
- Eat a well-balanced and a nourishing diet supplemented during pregnancy
- Have regular medical checkups throughout your pregnancy.



Prevention at the time of birth

- Delivery must be conducted by trained personnel, preferably in a hospital where all facilities are available.
- If the baby's head appears to be abnormally small or large, then a physician should be consulted, preferably a pediatrician.
- Breastfeeding should be started immediately after birth, where possible.

Prevention in Early Childhood Care

- Do not allow a child's temperature to rise above 38.3 degrees F, as this can cause febrile seizures
- Every child should be immunized against infectious diseases as per the recommended schedule of immunization.
- Take precautions against head injury and other accidents.
- Ensure that the child gets a well-balanced diet and clean drinking water.
- Do not allow a child to use hairpins, matchsticks, and pencils, to remove wax from the ears.

REMEMBER

Pregnant women must be made aware and educated about what to expect should they give birth to a baby with a disability, but they should not be made to feel guilty and scared. It is essential that parents seek assistance and that the extended family and friends also provide support if the mother gives birth to a baby with a disability. Where accessible and available, counseling services should also be provided. The health care practitioners at hospitals or local clinics can provide the necessary information and support.

Despite the joy that comes with the journey of caregiving, all caregivers face particular challenges in their personal, family, and community life as they raise their children. Regardless of the setting, children, particularly those with disabilities, experience various challenges in different periods of their growth as follows;

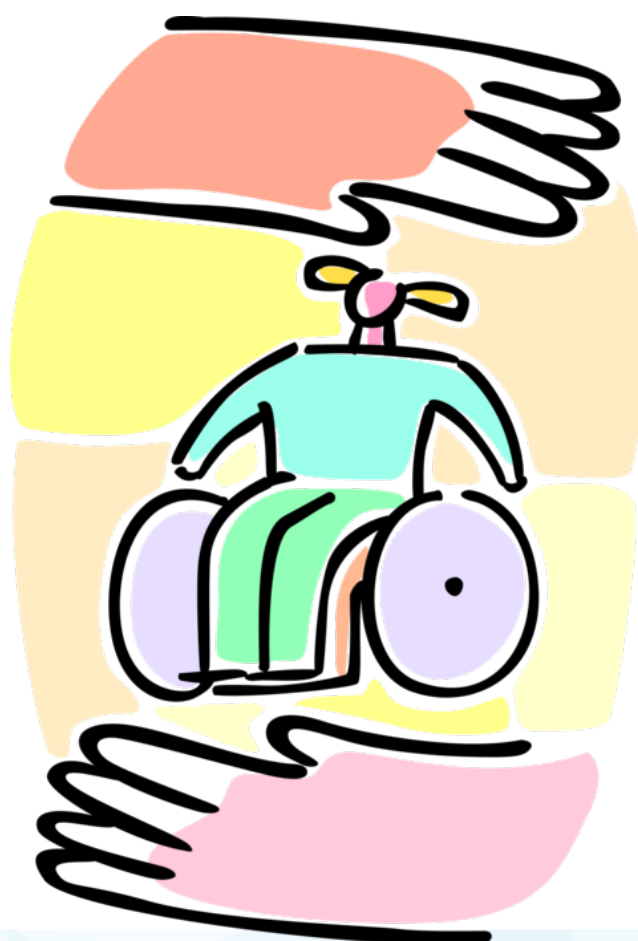
- Prenatal screening and termination of pregnancy
- Denial of appropriate medical treatment and care
- Rejection by family, relatives, and peers
- Isolation from community life in general
- Denial of the right to education and many other human rights
- Continuous medical treatments, some painful and unnecessary
- Denial of the right to participate in decisions that affect their lives
- Violence or abuse, namely physical, emotional, sexual, and neglect

Often, caregivers of CWDs experience immense challenges as they grapple with their caregiving roles. Many do not get support from their families and communities, who may not understand their situation.

Some problematic instances they experience may include;

- Lack of family support; family member and relatives may not accept the child and hence withdraw their support
- Lack of resources, primarily financial to provide for basic needs, education, and medical care
- Lack of knowledge and skills to address their child's condition or offer the necessary care
- Stigma and discrimination from their extended families and communities
- Barriers to access to essential services such as education, health care, and employment.

Having a child or family member with a disability can affect the family in many ways. It can have a severe effect on the mental well-being of the mother and





father due to the stress that comes with the associated challenges of raising a child with a disability.

- Marriages sometimes break down, and couples divorce when a child with a severe disability is born, and women are left to take care of the child.
- Those who do not have the means and resources or are afraid of stigmatization sometimes abandon their children. Caregivers and their families need to be supported to adjust to these profound changes.
- Being different can result in stigma and discrimination. Sometimes cultural or religious beliefs can encourage families and communities to believe that the birth of a child with a disability is a punishment or brings 'bad luck, and this is usually a misconception.
- Having a disability can cause a child to be perceived as being different. This perception can also spread to the rest of the family. Being different can cause exclusion. If someone looks different and acts differently, it can take extra effort for other people to feel comfortable with them.
- Disability can increase the chances of abuse of a disabled child. The child may be physically punished because of their disability; they may be shunned or neglected. They can sometimes be locked in the house or be physically restrained. This is sometimes justified by families who will say that they are trying to keep their children safe. Families need to understand more appropriate ways to maintain safety. It can mean that children with disabilities are bullied by other children in their community and by adults.
- Families of CWDs, including their siblings, may also experience the same stigma and discrimination. This can mean that the whole family becomes isolated. It is crucial to work together to find solutions. This can include families of children with disabilities helping each other, individually and in family peer support groups.
- Disability can contribute to increased poverty at the household level as parents take time away from income-generating activities. Siblings may be taken out of school to care for a brother or sister with a disability. Families are also required to meet the additional costs associated with disability, for example, payments for health care and transportation.

III. EARLY INTERVENTION

The early years of a child's life are a period of tremendous growth in all areas of development. Caregivers have a critical role in helping their children to grow and develop well from birth onwards. In addition to proper nutrition, a child needs stimulation to grow and develop. When a father encourages a child's interest and curiosity, the child reaches out to explore and learn more. Therefore, Intervention programs with parents of CWDs have far better child outcomes when fathers participate in the parent training together with mothers.

Early Intervention Services for children with disabilities

Early intervention services aim to support young children at risk of developmental delay or who have been identified as having developmental delays or disabilities.

Examples include;

- Specialized services such as medical; rehabilitation (e.g., therapy and assistive devices);
- Family-focused support (e.g., training and counseling);
- Special education and support to access mainstream services
- Referral for medical interventions as treatment, screening, or provision of assistive devices.
- Starting stimulation in collaboration with parents to stimulate language development.
- Provide adequate nutrition and supplementation.
- Specialist home-visiting services for children with disabilities.

Importance of early intervention

- Children with disabilities who receive good care during early childhood are more likely to become healthy and productive adults. This can potentially reduce the future costs of education, medical care, and another social spending.
- The first three years of a child's life are a critical period for brain development. Thus, if children with disabilities are to survive, flourish, learn, be empowered, and participate, attention to ECD is essential.
- If discovered early, some disabilities may be treated or subjected to corrective surgery
- With early intervention, we can learn how to support the child and manage the disability better.

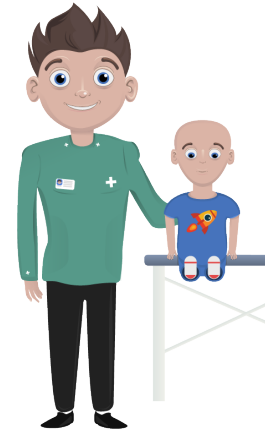
Available Services and Support Professionals

There are many services outside your community that could also benefit children either directly or indirectly. Here are some of them:

- **Hospitals and medical specialists;** you could visit a pediatrician, ear, nose, and throat specialist, eye specialist, orthopedic specialist, or a child psychiatrist
- **Physiotherapists;** help restore and improve the way a child's body moves and functions using techniques to improve movement and mobility, strengthen muscles, and improve coordination and motor skills. The physiotherapist will also

advise the child and parents about special assistive devices that the child can use to enhance the function of her body or her hands, arms, and legs.

- **Occupational therapist;** focuses on practical and self-help skills that will improve the child's daily activities such as dressing, feeding, toileting, playing, and interaction with other children. They will advise the child and parents on what they can do at home to improve their quality of living. They will also inform the child and parents about special assistive devices that the child can use to enhance their daily activities.
- **Speech and language therapist;** uses special techniques to develop or bring about improvement in communication skills, including speech and language abilities. The speech and language therapist is also able to help children who have autism and their parents. They advise about what they could do to improve the child's daily interactions.
- **Nutritionist or dietician;** a child who has a health condition caused by a nutritional problem may be referred to a nutritionist or a dietician in the hospital who will advise the child and parents what kind of food the child should eat, at what times and how it may best be prepared.
- **Social service officers;** can help parents obtain certain kinds of equipment prescribed for a child by a doctor. They may help children and parents get, for instance, hearing aids, spectacles, wheelchairs, and crutches.
- **Child rights promotion officers;** guide any matters related to the children and for advice and help that you may need, including dealing with child abuse perpetrators.
- **Education office;** parents of children who have a disability can get advice and help from the local Education Office to get a child in a primary school. They may also provide teaching and learning materials such as books.
- **Non-Governmental Organizations;** there may be non-governmental organizations working in your area who may be interested in supporting early childhood education in different ways. You could find out whether there are such possibilities either from the government offices in your area.



Where to seek Assistance:

Kenya Institute of Special Education (KISE)

Kasarani, Off Thika Road Nairobi. Email: info@kise.co.ke;

Website: www.kise.co.ke

Ministry of Gender, Children and Social Development,

Building, Block A, Eastern Wing, Floor. Email: infomation@gender.go.ke

Special Education Professionals

Email: sep_professionals@yahoo.com

The Action Foundation

Hse H52, Olympic Estate, Off Kibera Drive. Email: info@theactionfoundationkenya.org

Website: www.theactionfoundationkenya.org

IV. CHILD NEEDS AND OUR ROLES

Children require food and water, sanitation, and access to health services to survive.

BUT THEY ALSO NEED...

affection, loving attention, mental stimulation, guidance, and support to develop and grow in a secure and positive environment.

Because there are so many variations and types of parents and caregivers, there is a definite need for clear information, experience, support, education, and guidance to provide a safe, nurturing, and positive learning environment for their child to develop and grow. They also have esteem needs, social needs, security needs, and physical needs

Children's emotional needs could include providing;

- Attention
- Acceptance
- Appreciation
- Encouragement
- Love and affection
- Respect
- Support
- Comfort
- Approval
- Security

Keys to encouraging attachment as fathers could include;

- Make yourself available.
- Be attentive to your child's cues.
- Respond quickly and appropriately.
- Be warm, positive, and caring.
- Follow your child's lead and co-operate with them on how they play and interact.
- Avoid over-stimulating your child as you interact.



Emotional needs

- Pick one or two emotional needs that you will actively try to meet for your child this week.
- Identify specific ways you can try to meet this need.

Caregivers have the role of providing a positive environment that allows for a child to develop and grow. This includes physical support, emotional support, psychological support, and protection.

Specific roles of fathers in ensuring

Early childhood care and responsibilities are often linked to the mother, and fathers' roles are overlooked. Research, however, shows that a father's involvement in the early childhood years is associated with positive child developmental and psychological outcomes over time.

This means, therefore, that fathers have a crucial role to play in the lives of their children. Further studies of early childhood development and education have shown that children whose fathers are involved in their lives do better at school and feel more confident. Conversely, children with little or no contact with their fathers are more likely to use drugs and abuse alcohol, and boys are more likely to turn to crime and violence. Children will feel more secure when their fathers protect them, love them, and participate in their lives, especially during the early years.



The fathers' roles in nurturing their child's development can be, but is not limited to, the following:

- Comfort their child when he/she is sad or needs reassurance.
- Listen to and take an interest in what their children do and say.
- Be a good role model for their children; help the child in his/her learning life or educational experiences.
- Make time for their children. Do activities around the house and help with feeding, washing, dressing their children, and playing with their children.
- Allow their children to express their feelings when they are sad or hurt.
- Find non-violent ways to discipline their children [Note: If hitting a child causes harm to the child, it can be considered abuse. Using insulting words on the child can be emotional abuse.]

What is it like to be a father of a child with a disability?

Our experiences of being fathers of CWDs so far; Think about any:

- Surprises
- Disappointments
- Hopes
- Joys of being a parent so far

V. QUESTIONS FATHERS ASK

How can I communicate with my child with a disability and how do I know when he/she wants to communicate with me?

Some children with disabilities will be able to speak with you. Others will not be able to talk. But they do communicate, even though they don't talk. For example, when a newborn baby comes into a family, that baby communicates without saying. You learn the baby's likes and dislikes by whether they smile, or laugh, or whether they cry. The same occurs with children with disabilities who can't speak. They tell you what they like by smiling or laughing, and what they don't like by crying or making an upset face. For deaf children, it is recommended that fathers learn sign language to communicate where possible.

What can I do in my day-to-day to make sure I'm stimulating my child and his/her brain development?

Children are stimulated by everything in their environment: by the sounds, by your smile, by all interactions. So, suppose your child with a disability is around you, make sure that you spend time talking with them, explaining what you're doing in simple language. You can also smile with them, tell them all about their environment, and make noises around them to respond to noises.

You can also stimulate them by directly playing with them, making little toys in the home, putting stones in a bottle, and shaking it by waving ribbons in front of their eyes, different colored stripes. There are many things that you can do with items around your house.

How do I play with my child with a disability?

Children with disabilities enjoy playing just like any other child. They appreciate it when you read to them, showing them pictures, tickling them, hugging them, cuddling them. They respond to you with laughter and smiling. If they don't like a particular play that you are doing, they will tell you. They will stop laughing, and they'll stop smiling. Try something else. You will find something because you know them best.

If I don't have time to play or money to afford toys, what can I do?

If you don't have a lot of time to play with your child, there may be other family members in your home who will be able to play with your child with a disability. Brothers and sisters are great around children with disabilities. They stimulate them because they talk to them a lot and they play with them. They don't seem to be concerned about whether a sibling has a disability. They play with them just like anyone else. If you lack money to purchase toys, you can use materials available in your home to make various play items, such as a ball made out of socks and a shaker with small rocks in a bottle.



VI. ADVOCACY

Why we should advocate

- We can share our own valuable experience with our child
- We are the experts about our children and know what they need.
- We are always with the child
- A child is served best if parents and professionals work together.
- NO ONE cares about our child as much as we do and can best speak for them until they are old enough to speak for themselves.

To be an effective advocate the following skills can be essential:

1. Understand Your Child's Disability

- It helps you understand the options for raising a child with this disability
- It enables you to ask educated, informed questions
- Allows you to understand if the services are appropriate to meet the needs of your child

2. Know the Key Players

- This will help you to influence someone to make a change you think is necessary for your child
- You need to know who has the authority to make decisions and changes; is there a hierarchy? Is there someone in the system with a higher rank or more authority? If one person can't or won't help you, who is the next person with higher responsibility who might be able to help you?

3. Know Your Rights and Responsibilities

- Knowing who is in charge is not enough. Parents need to participate from a position of knowledge as much as possible.
- Each agency or service provider has guidelines on how they work. They have procedures, forms, policies, and sometimes laws and regulations. Do your homework

4. Become Well Organized

- Most agencies and services require documents, data, records, etc. So be well prepared by organizing what you have.
- Keep good records and details about your child since you never know what you might need in the future.
- Also, keep important contacts that will be handy.



VII. CHILD PROTECTION

- Children have a right to good health care, safe water, nutritious food, clean and safe environment.
- They have a right to good and quality education.
- They have a right to play and rest.
- They have a right to be protected from kidnapping
- They have a right to give their opinions and for adults to listen and take it seriously.
- They have a right to get information that is important to your well-being.
- They have a right to be protected from being hurt or mistreated.

REMEMBER

Many children around us are experiencing child abuse. Children can be abused physically and emotionally. All children have the same rights no matter who they are, where they live, whether boy or girl, rich or poor, with or without disability.

When people want to hurt children, call them bad names or do bad things to them, we say they are abusing them. Some of the ways children are abused include:

- Hurting them on the body by burning them, kicking them, beating them badly, etc.
- Saying with words that make them feel very bad about themselves.
- Abandoning, neglecting, and locking them. up
- Sexually defiling them
- Exposing them to dirty adulterated images or content
- Refusing to give them food, take them to school or hospital even when we can afford it.
- Forcing them to do jobs that are very difficult for them.
- Telling children to take and sell alcohol and other drugs of abuse.

In conclusion, it is important to note that;

- Children are abused by mainly familiar people or those to them
- Many people are afraid to speak up even when they know that a child is being abused.
- We should not allow child abuse to continue around us– every child has a right to be protected.

We can take action to STOP CHILD ABUSE by reporting to the following;

- The Chief or Village Elders
- The Police
- Child Protection Officers including CHVs
- Child Rights Organizations and NGOs

CONCLUSION

Write down key things that you have learned on your role regarding caregiving for CWDs

- _____
- _____
- _____
- _____
- _____

Write down key things you will do to improve your role regarding caregiving for CWDs

- _____
- _____
- _____
- _____
- _____



NOW I KNOW

The Action Foundation has published the **Tuwalinde Guide for Fathers of Children with Disabilities** with funding from Comic Relief; as part of the Caregiving and Safeguarding of Children with Disabilities Project implemented in partnership with the Centre for Enterprise Development and Innovation (CEDI).

For further inquiries, please contact:

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