



# A Parent Guide on Understanding Autism: for Kenyan Parents

# Acknowledgements



This publication is not the work of one single individual but a collaboration of many including Dr. Lincoln Kamau, PhD, BCBA-D© (team leader), Doreen Katha, Jennifer Mbogo, Isaiah Khang'ati, Trixie Pujol, Naomi Kiemo, kimani Alice, Karay Blue, Alice mundia and Tisha Nair.

This publication may be distributed as is or, at no fee for autism dissemination.

## **Introduction**

If you are a parent, guardian or a relative of a child who has been diagnosed with autism, this booklet is written for you.

Receiving a diagnosis of autism can be an overwhelming experience for any parent.

The goal of this booklet is to assist you make informed decisions regarding the treatment and education of your child.

Included in this booklet are questions that parents like yourself frequently ask when their child receives a diagnosis of autism and brief answers to guide you.

## **What is Autism?**

Autism as is commonly referred is short for Autism Spectrum Disorder (ASD).

Autism is a developmental disability that can cause significant social, communication and behavioral challenges. There is often nothing about how children and adults with autism look that sets them apart from other people, but people with autism may communicate, interact, behave, and learn in ways that are different from most other people. You may have observed some of these differences in your child's development. The learning, thinking, and problem-solving abilities of people with

autism can range from gifted to severely challenged.

A diagnosis of autism now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism.

## **Signs and Symptoms**

Children and adults with autism often have problems with social, emotional, and communication skills. They might repeat certain behaviors and might not want to change in their daily activities. Many people with autism also have different ways of learning, paying attention, or reacting to things. Signs of autism begin during early childhood and typically last throughout a person's life.

Children or adults with autism might:

- not point at objects to show interest (for example, not point at an airplane flying over)
- not point to request desired objects'; (such as food, toys)
- not look at objects when another person points at them

- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled, or might cuddle only when they want to
- appear to be unaware when people talk to them, but respond to other sounds
- be very interested in people, but not know how to talk, play, or relate to them
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language
- have trouble expressing their needs using typical words or motions
- not play "pretend" games (for example, not pretend to "feed" a doll)
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- lose skills they once had (for example, stop saying words they were using)

Diagnosing autism can be difficult since there is no medical test, like a blood test, to diagnose the disorder. Doctors look at the child's behavior and development to make a diagnosis. It is important that you let your doctor know of any behavior and developmental concerns you have with your child before the diagnosis is confirmed and throughout their development.

Autism can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable.

However, many children do not receive a final diagnosis until much older. This delay means that children with ASD might not get the early help they need.

## **What causes Autism?**

The answer is simple we don't know.

While the definitive cause or causes of autism are not clear, it is clear that autism is not caused by bad parenting. Autism is neither caused by anything the mother did before her pregnancy, during the pregnancy or after birth. Nor is it caused by a curse or witchcraft.

Most recently some people have had concerns that autism might be linked to the vaccines children receive, but the best scientific evidence does not support either of these factors. They both have been proven false over and over again.

However there are certain risk factors for autism. These factors that make a child more likely to have autism. These environmental, biological and genetic factors include:

- Most scientists agree that genes are one of the risk factors that can make a person more likely to develop ASD.
- Children who have a sibling with ASD are at a higher risk of also having ASD.

## **How common is Autism?**

We are not sure what the numbers for children and adults with autism are in Kenya. In countries like the United States of America (USA), recent estimates indicate that 1 out of every 88 children is diagnosed with autism, and that boys are diagnosed almost 5 times more frequently than girls. Some estimates indicate that 1 out of every 54 boys is diagnosed with an ASD. These occurrence rates suggest that autism occurs more frequently than childhood cancer, juvenile diabetes, and pediatric AIDS combined. There is not one single explanation for these different rates of diagnosis between boys and girls, just as there are is not a single explanation of what causes autism. It can be assumed that the numbers in Kenya are similar to that of the USA.

## **What behaviors and challenges are common in children with autism?**

Children who are diagnosed with autism show difficulties mostly in three main areas: language and communication, social interactions, and repetitive

behaviors/or restricted interests and patterns of doing things. Additional symptoms that are usually present include sensory interests (e.g., seeking out textures to feel, smelling objects that are not typically smelled) and sensory aversions (e.g., covering ears in response to loud noises such as a fire truck, low flying plane or toilet flushing; refusing to wear certain types of clothing like socks). Children also tend to show motor difficulties with some gross motor skills (e.g., running, catching a football, skipping) and with some fine motor skills (e.g., handwriting, buttoning a shirt, using a spoon). Many children with autism also have attention and learning difficulties that interfere with performance in the classroom and prevent them from functioning at their best potential. It is not uncommon for children with autism to be thought of as having attention deficit-hyperactivity disorder (ADHD) prior to their ASD diagnosis.

## **I hear there are medical problems that go along with autism?**

Yes, there are some medical problems that go along with a diagnosis of autism. But this does not apply to all children with autism. If you have any health concerns about your child. Have them evaluated by a good doctor who has expertise in the medical management of children with special needs. It is not uncommon for children with autism to experience medical problems such as, Gastrointestinal Issues with symptoms like constipation, reflux, and diarrhea, sleeping difficulties feeding issues, or seizures. Often, treating these symptoms can result in improvements in behavior because the child is feeling better and is more likely to participate with other kids in your family life.

## **Is there a Cure for autism?**

You may have heard about children who have recovered from autism. Experts are not certain about whether or not this is possible. Evidence in the medical

community suggests that a small number of children with autism have progressed to the point where they no longer meet the criteria for a diagnosis of autism.

Experts say that stories about such recovering from autism of some children range from the assertion that the child was misdiagnosed to the belief that the child had a form of autism that may resolve as he matures to the opinion that the child benefited from successful treatment.

There is no way on knowing what percentage of children with autism will recover, if any or what factors can predict which ones will and which ones will not. The most promising connection in recovery from autism is usually reported in cases of children who started with intensive early intervention. While this is not a cure, most children with autism will benefit from intervention. As such believe in your child's potential for significant progress and start interventions as soon as you can.

## **Can my child be cured with medications?**

No, there is no medication in pill or liquid form that can "cure" autism. Medications for children with autism when prescribed by your doctor target specific symptoms commonly associated with children with autism. These symptoms may include aggression, attention difficulties, anxiety, obsessive-compulsive behaviors, or depression.

Most children with autism do not need medication. However, some children have benefited from the use of medications to manage behavioral and psychological difficulties like those mentioned previously. Finding a good doctor with whom you can talk about the benefits and risks of medication for your child will be helpful. Be careful because children with autism do not always respond in a typical manner to medications.

## **What about dietary and nutritional interventions?**

There is a lot of talk about diet and nutritional interventions as treatments

for children with autism. Removal of gluten (a protein found in barley, rye, and wheat, and in oats through cross contamination) and casein (a protein found in dairy products), is a popular dietary treatment for symptoms of autism for many families.

The idea behind these diet interventions is that proteins are absorbed differently in children with autism and some of the physical and these proteins may cause behavioral symptoms displayed by children with autism. There have not yet been sufficient scientific studies to support this theory, many families report that dietary elimination of gluten and casein has helped regulate bowel habits, sleep activity, habitual behaviors and contributed to the overall progress in their individual child.

Because there is not a specific laboratory test that can predict which child with autism will benefit from such dietary and nutrition interventions, this is a route you take at your own risk. If you chose this path, a medical doctor and a nutritionist should supervise any trial of dietary restriction. This will make sure that the child is receiving adequate nutrition.

Dairy products are the most common source of calcium and vitamin D in young children in Kenya. Many young children and families in Kenya depend on dairy products for a balanced protein intake. It is therefore important to have other alternative sources of proteins and other nutrients that your child may miss out if you are considering dietary interventions.

Elimination of gluten products from a child's diet may also affect the overall fiber and vitamin content of your child's diet.

Some families go for vitamin supplements. This too may have both positive effects and side effects. It is important that you consult with a nutritionist or your medical doctor before putting your child on a vitamin supplement.

## **How is Autism treated?**

Because there are no medical interventions for autism, treatment for autism is usually in a form of intensive treatment therapies that will involve a lot of people in your child's life. Some of this therapy will take place at school. Some

programs may take place in your home and some programs are delivered in a specialized center or a hospital.

It is important to note that in the language of autism care, experts may use the terms “treatment” and “therapy” interchangeably. “Treatment” in this case means “management” as there is no “cure” but with proper intervention, a child will make noted progress. The word “intervention” may also be used to describe a treatment or therapy.

Treatments for autism mostly address the core deficits a child with autism has, mainly in the areas of Social, Communication & Cognitive Issues. Treatment may also address behavior challenges your child may be having.

If your child has medical conditions, such as Allergies, Gastrointestinal Issues, Sleep Disturbances, or Food Intolerances, these will be treated too.

Sometimes Occupational Therapy or Speech & Language Therapy and Physical Therapy may be integrated as part of treatment if your child will benefit from these therapies.

There is not a “one-fits-all” treatment package for autism. Your child’s treatment program will depend on his or her individual needs and strengths. Some children will get one or two treatments while others will get multiple treatments at once.

Before your child’s treatment begins, work with your medical doctor, special education teacher, speech therapist and other professionals working with your child to help you prioritize therapies based on your child’s comprehensive evaluation. Once you have your priorities in order, it is important to talk to a parent with experience on autism or someone else with know-how on these therapies to make sure you have a thorough understanding of what is involved before beginning any therapy for your child.

Never choose an intervention for your child before you understand the possible risks and benefits for your child.

Whenever possible after therapy has been on your child, observe the therapies in action.

## **Now that my child has autism, what do I do?**

While this list is not exhaustive, here are a few steps you could take to begin with.

### **Step # 1 -Complete Evaluations**

If your child has not completed their evaluations, this is the first place to start. This may include evaluations by other specialists other than your medical doctor for any concerns you may have had (e.g., evaluations with a speech and language therapist, an ear specialist, and eye exam).

### **Step # 2-Research Treatment Options**

For your child to get the best interventions possible, you have to be informed. Start to read material on autism and available therapies in your area. Locate experts who are willing to consult or give their time to you for free. Ask questions that will help you understand the treatment options that are available and what might be right for your child.

### **Step # 3 – Build a team**

Your child will need a therapy team of therapists, special educators, nutritionists, behavior analysts and other

such providers. Through your research, via county resources and talking to other parents who may know of therapists with time available for your child. You can successfully assemble a team.

### **Step # 4 – Home safety**

Autism presents a unique set of safety concerns for parents. Most children with autism are not aware of dangerous or poisonous substances in the home. Some children with autism may display behaviors like running away that may pose as a danger. If your child is at a day care or with family or relatives when you are away for work on any reason, ensure those environments are safe too.

Some children with autism are also often attracted to water sources such as in rivers, ponds and lakes. If you live near one of those water bodies, be aware of the dangers of drowning and make any plans if necessary to ensure your child does not end up near those large bodies of water.

### **Step # 5- Training and seminar**

Your child's therapy will probably be long term, become a learner. Look for

seminars and trainings on therapies coming near you. Be informed and use some of the methods you will learn from these workshops where relevant to assist your child have the best chance of obtaining their goals.

### **Step # 6- Look for a support group**

As you embark on therapy for your child, do not isolate yourself. Make connections with other parents who have children with similar challenges. If there is a support group near you join one. Parents are amazing resources and will help provide emotional and practical support. You will need the support of good friends and family members too. You may also seek support from your local church, mosque or temple.

### **Step #7 – Take care of yourself**

Do not run on an empty stomach. Once in a while take time off and take care of yourself. Your child's welfare is of great importance but to be able to take care of your child's needs, you need to be in good health yourself. Stay healthy.

## **I feel sad, angry and lonely, is this normal?**

Yes, this is normal. No parent is ever prepared for a diagnosis of autism, or even any diagnosis on his or her child. It is likely that you will experience a range of emotions in the next few weeks and months. You may be going through some of those emotions now.

As a parent, you want your child to get better, sometimes you will ask yourself why your child. Why you?

This is normal. Immediately after you get your child's diagnosis you may feel shocked or confused. You may question the diagnosis or search for another doctor who will tell you something different. You probably were not ready to accept the initial diagnosis. It is hard.

As time goes on you feel sad, a lot of sadness. You have every right to feel sad and to express it in ways that are comfortable. Crying can help release some of the tension that builds up when you try to hold in sadness. A good cry can get you over one hurdle and help you face the next. Get the support of a family or close friend. You can cry alone too.

With time, your sadness may give way to anger. You may find yourself angry at your child, your spouse, your friends and family, the world and everything in it. You may even feel resentment toward parents of typical children. Your anger may come out in different ways like overreacting at small things, snapping at people, even screaming and yelling. Again this is normal. This is a healthy and expected reaction to feelings of loss and stress that come with the diagnosis of autism for your child.

You may also go through periods of refusing to believe what is happening to your beloved child. During this time, you may not be able to hear the facts as they relate to your child's diagnosis. Don't be critical of yourself for reacting this way. Your family and spouse will probably say you are in denial. Again this is normal, denial is a way of coping. It may be what gets you through a particularly difficult period. You must, however, be aware of that you may be experiencing denial so that it doesn't cause you to lose focus on your child's treatment.

Hopefully when someone, a doctor, a therapist or a special education teacher, tells you something that is difficult to hear

about your child, consider that they are trying to help you so that you can address the problem. Do not lash out at them. It is important not to push away people who can give you helpful feedback and monitoring of your child's progress.

Whether you agree or not, try to be kind to them. If you are angry, try coming to discuss their information when you have had a chance to calm down.

In this period of intense emotions after your child is diagnosed with autism, you may feel lonely and isolated too. This loneliness may also come from the fact that in your new situation you simply do not feel you have the time for family or friends; again this is a normal process. You are going through a hard time that only you alone can understand.

At the end of the day, you may get to a place where you accept that your child has been diagnosed with autism.

Accepting the diagnosis is a good start. It means that you are ready to start working for your child's treatment and therapy. Go now and get your child a treatment team.

Remember also that other members of your family (e.g., your spouse) may be going through the same emotions as you are. They could be at a different level and

may take longer to come to acceptance, so do not push things on them. Be patient.

## **What resources are available to help me learn about my child's autism?**

The following sources may provide information related to autism. It is important to be a careful consumer when consulting with these groups or other autism resource centers.

### **Autism Lights Inc.**

info@autismlights.org

Autism Lights provides free Tele consults with parents and other professionals working with children with autism in Kenya. See <https://teleautism.org/>

### **The National Council for Persons with Disabilities**

<http://ncpwd.go.ke/>

See your regional officers on the contacts page

### **The Kenyatta National Hospital**

Hospital Road, Upper Hill, Nairobi 00202, Kenya

Phone: +254 729 406939

### **Kaizora Institute, Nairobi, Kenya**

[www.kaizora.com](http://www.kaizora.com)

Phone: +254 772 444794

### **Kenya Autism Alliance**

@Kenya Autism

### **Special Education Schools in Kenya**

There are over 90 special education schools in Kenya that provide specialized education. The ministry of Education through Kenya Integrated Education Program encourage integrating children with disabilities into ordinary school rather than having special schools for them. This way they can interact with other children and those without disabilities can learn to accept them.

### **List of Special Schools in Kenya**

- Acorn Special Tutorials
- Aquinoe Learning Centre
- Augustana Academy
- Bright Hill Special School and Assessment Centre
- Chekombore Special School for the Deaf
- Dagoretti Special School
- Ebeneza Mercy Mission Children's Home
- Embu Special School for Mentally Handicapped

- Homa Bay Children’s Home Academy
- Iten School for the Deaf
- Kaaga School for the Deaf
- Kambui School for the Deaf
- Kapsabet School for the Deaf
- Karatina Special School for Mentally Handicapped
- Karen Technical Training Institute
- Kenya Community Centre for Learning – KCCL
- Kenya Institute for the Blind
- Kenya Society for Deaf Children
- Kerugoya School for the Deaf
- Kibarani School for the Deaf
- Kibos School for the Blind
- Kitui School for the Deaf
- Kuja Special Secondary School for the Deaf
- Lily of the Valley School
- Links School and Tutorials
- Mathare Special Training Centre
- Model Center for Deaf Education and Training
- Mombasa Secondary School for the Physically Handicapped
- Mumias Primary School for the Deaf
- Oshwal Jain Primary School
- Rev. Muhoro Secondary School
- S.A Joytown Secondary School
- Sight Savers International
- Siuna Community Children’s Home
- The Grangeville School
- The Salvation Army Thika Primary
- Tumu Tumu School for the Deaf
- Ziwani School for the Deaf

## **Educational Assessment and Resource Centers**

If you have a child with disability or suspect has problems, please do not feel ashamed, you can get help by going to your district education office.

Educational Assessment and Resource Centers are one stop shop where you can learn, get information, counseling and support for the disabled. Every district in Kenya has one Assessment Centre attached to District Education Office. For example, Nairobi has three centers; KISE (Kasarani), St. Annes Primary School (Eastlands) and Kenyatta National Hospital.

Additionally, the education centers can assist with:

- Identification and assessment of disabilities
- Guidance and counseling of parents of children with special needs
- Running courses for parents of children with Special Needs
- Assist with the establishment of special needs units (special class) in regular schools
- Making referrals of children with special needs to special schools, units, integrated programs or for

medical examination and treatment.

- They can run seminars for teachers handling children with special needs, field officers, local administrators, health and social workers
- And collect information which forms the basis for central planning and special needs education survey research

If you have any questions about this publication or want a free consult with a Board Certified Behavior Analyst (BCBA) related to Autism,

feel free to contact Autism Lights Inc. at [info@autismlights.org](mailto:info@autismlights.org)

Autism Lights also provides free Tele consults with parents and other professionals working with children with autism in Kenya. You can also sign up at our Get Started Today page at [www.teleautism.org](http://www.teleautism.org)