A STATUS REPORT BY BCB AUTISM FOUNDATION

# AUTISM 101 INKENYA



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Best Can Be Foundation is a non-profit organization dedicated to supporting children and caregivers of children on the Autism Spectrum Disorder (ASD) in Kenya. We aim to create a safe space and resource center specifically tailored to the needs of neurodivergent individuals in Kenya. Our foundation is driven by firsthand knowledge of the challenges faced by children with ASD and their caregivers.

### **Vision**

Envisioning a Kenya that embraces and celebrates autistic children, our vision is to be a comprehensive resource. We strive to create an inclusive society where every autistic child thrives, achieves their full potential and becomes the best they can be.



**Mission** 

To empower children with Autism Spectrum Disorder (ASD) and their caregivers with the knowledge, tools, and opportunities they need to unlock their full potential and embrace the journey of self-discovery, growth, and success.

# **Values**Our values are guided by:



### **BCB's Objectives**

We aim to be a transformative force in the lives of children with Autism Spectrum Disorder (ASD) and their caregivers. We strive to:

- Ol Build the capacity of caregivers on effective autism management, equipping them with the knowledge and skills necessary to provide the best care and support to their children.
- O2 Mobilize resources to ensure that every child on the spectrum has access to essential therapies enabling them to overcome challenges and develop vital life skills.
- O3 Create widespread awareness about autism in underserved communities in Kenya, bridging the knowledge gap and reducing stigma, thus fostering a more inclusive society.
- O4 Advocate for and work towards increasing the number of qualified therapists and special needs



education professionals in Kenya, ensuring that every child with autism receives individualized care and attention.

Through our unwavering commitment, collaborative partnerships, and tireless efforts, we strive to create an inclusive society where the lives of autistic children are celebrated for their uniqueness.

We believe that when we support them in becoming confident, capable, and independent individuals they will lead fulfilling lives within their communities, unleash their full potential and be the best they can be.

# What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD) is a neurological and developmental disorder characterized by impaired social interaction, communication difficulties, and restricted and repetitive behaviors.

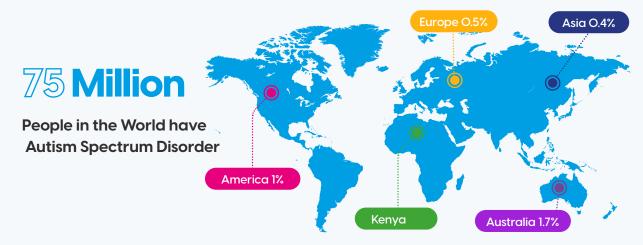
Although the exact cause of ASD is still unknown, it is believed to be caused by differences in brain structure or function. People with ASD may exhibit unique ways of behavior, interaction, and learning.

They may face challenges in social interactions, nonverbal and verbal communication, and may require different levels of care and support.





However, with the right support and early intervention, individuals with autism can learn, develop, and lead fulfilling lives.



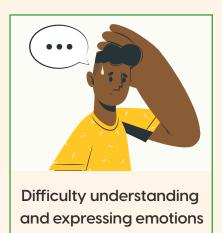
**Source:** Centers for Disease Control and Prevention (CDC) 2023

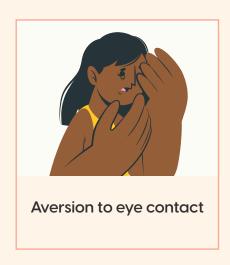
### Signs and symptoms

of ASD Signs and symptoms of ASD can manifest in various ways in about in various ways, including but not limited to:

### Social communication deficits:

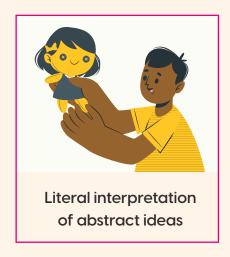














Difficulty in conventional social relationships

### Restricted interests and repetitive behaviors:



Inflexibility and resistance to change



Overly focused on specific subjects or topics



Difficulty tolerating changes in routine and new experiences



Sensory hypersensitivity, such as aversion to loud noises



Stereotypical movements (e.g., hand flapping, rocking, spinning)



Organizing objects or toys in a specific manner

### **Diagnosis**

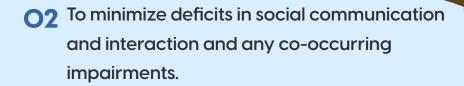


ASD can be identified in children as early as 12 to 18 months of age, and early intervention is proven to influence outcomes, the American Academy of Pediatrics' (AAP) recommends screening all children for symptoms of ASD through:

- General developmental surveillance at all clinic visits.
- Standardised autism-specific screening tests at 18 and 24 months of age in their primary care visits.

### Why provide interventions:

To maximise functional independence by facilitating learning and acquisition of adaptive skills.



O3 To minimize or prevent self-harming/ problematic behaviors or those that may interfere with acquisition of functional skills.



### Kenya Landscape

Official data on autism prevalence in Kenya is not available, but the Autism Society of Kenya (ASK) estimates that it could be as high as 4% - approximately one autistic child for every 25 children.

The prevalence of Autism Spectrum
Disorder in Kenya has recently been
reported to be on the rise. This rise can
be attributed to increased awareness
and diagnosis.

Unfortunately, autism has often been misdiagnosed as a mental illness or retardation in Kenya. Children on the spectrum are often subjected to mistreatment, isolation, and stigmatization due to misconceptions.

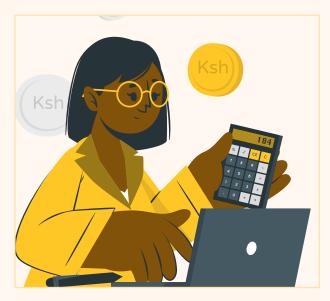
Kenya's constitution prohibits discrimination against persons with disabilities in Article 27(4), guarantees free, compulsory basic education for all children (Article 53(b), and ensures access to integrated educational facilities for persons with disabilities (PWDs) in Article 54.

However, therapists are mostly concentrated in urban areas.
Rural areas have fewer therapists compared to urban areas, leaving children with autism in the rural areas underserved.

# Cost prohibitive nature of interventions



Various interventions for Autism Spectrum
Disorder (ASD) encompass early behavioral
approaches, speech and occupational therapy,
social skills training, educational assistance,
medications, and the ongoing expenses
associated with managing the condition and



overall functioning. The substantial expenses associated with these interventions, combined with inadequate insurance coverage and inconsistent accessibility, can impose a significant strain on families.

This can potentially result in disparities in accessing crucial services, thereby impeding the ability of individuals with ASD to receive the comprehensive support needed for their optimal development and well-being.

# Essential Support in Autism Intervention:



# Occupational and Behavioral Therapy:

#### Occupational therapy:

Occupational therapy is a healthcare profession that aims to help people of all ages regain, develop, or maintain the skills necessary for daily living and meaningful activities (occupations).

#### Behavioral therapy:

Behavioral therapy, on the other hand, is a form of psychological treatment that focuses on modifying problematic behaviors and promoting positive behavioral changes. It is primarily used in the context of mental health and emotional disorders.

Occupational therapists play a crucial role in assisting individuals with autism.

By targeting sensory integration difficulties, occupational therapy helps regulate the child's nervous system, reduce anxiety, improve attention and performance, and develop skills for handwriting, fine motor skills, and daily living.

Occupational therapy aims to minimize barriers to learning and maximize independence in daily activities at home, school, and community life.

Therapists interviewed in this study reported a high number of children requiring therapy. Hence, they were overwhelmed by bookings from patients who can afford their services.

The respondents recommended that the government should incorporate Occupational Therapy in the National Health Insurance Fund (NHIF) in order to ensure that (OT) is accessible to low-income families.

This will result in the provision of long term rehabilitation to special needs children at an affordable rate.



# Occupational therapist Insights and Qualifications



Accredits occupational therapists

W.H.O recommends:



### Per 1 Million People

This translates to 40,000 OTs required in Kenya.

In Kenya there are:-

4,000 ots



OTs work for the government

"Chair, KOTA, 2023"



### Occupational therapist steps to certification:

Step 1:

#### **Attain Educational Qualification**

There are various institutions that offer courses in Occupational Therapy (OT) such as:

#### Jomo Kenyatta University of Agri & Tech:

Bachelors of Science in Occupational Therapy

#### Kenya Medical Training College:

Higher diploma in Community Based Rehabilitation
Diploma in Occupational Therapy

#### Presbyterian University of Eastern Kenya:

Bachelors of Science in Occupational Therapy

Step 2:

#### Join a Professional Body

The professional body in charge of OTs is Kenya Occupational Therapists Association (KOTA).

Step 3:

#### **Acquire a license**

KOTA is the body in charge of issuing licenses to OTs.

### Speech Therapy:

**Speech therapy:** also known as speech language therapy or speech-language pathology, is a specialized form of therapeutic intervention designed to assess, diagnose, and treat communication and swallowing disorders.

Speech-language therapy helps individuals with autism improve their verbal, nonverbal, and social communication skills.

It addresses speech deficits, semantics, and pragmatic difficulties, enabling individuals to better understand and engage in conversations and interpret body language and facial expressions.



# Speech therapist Insights and Qualifications

There are

# Fewer than 40sts in Kenya

Licensed & Practising

"(Speech therapist, 2023)"

1:50,000

Is the ratio of speech therapy patients.

"(ST Eldoret 2O23)"

### ATLSK & KPOA

Oversees speech therapists



### Speech therapist steps to certification:

Step 1:

#### **Attain Educational Qualification**

There are various institutions that offer courses in Speech Therapy such as:

#### Kenya Medical Training College:

Higher diploma in Speech and Language Therapy

#### **Kenyatta University:**

Masters in Speech and Language Pathology

Step 2:

#### **Join Professional Body**

The professional body in charge of STs is Association of Speech and Language Therapists Kenya (ASTLK).

Step 3:

#### Acquire a license

ASTLK in association with Kenya Health Professionals Oversight Authority **(KPOA)** is in charge of issuing licenses to STs.



### Special Needs Inclusive Schools & Teachers:

Special education schools or inclusive mainstream schools are equipped with qualified special needs educators and offer tailored education programs, within Individualized Education Programs (IEPs).

These programs identify a child's strengths and weaknesses, set goals and objectives, and provide individualized attention and instruction to facilitate learning, skill development, and overall well-being.

Shadow teachers or learning support assistants are assigned to an individual student in the classroom to help them access concepts taught at their individual pace.

In 2021, out of the 1,528 students who graduated from Kenyatta University with a Bachelor of Education (BEd), only 128 (8%) specialized in SNE.

According to the respondent who is a lecturer at Kenyatta
University, the few numbers of students specializing in SNE is as a result of the heavy workload required by students specializing in an SNE course.

She added that BEd (Special Needs Education) is like two degrees in one. Students enrolled for a BEd (Special needs education), have to take two other teaching units.



### Special Needs Inclusive Schools & Teachers:

The Kenya Institute of Special Education (KISE) requires applicants who intend to specialize in SNE, to have graduated with a BEd, Early Childhood Development Education (ECDE), or be a P1 teacher, examined by the Kenya National Examinations Council (KNEC).

Furthermore, Higher Learning
Institutions will start receiving s
tudents who have completed the
Competency Based Curriculum
(CBC) creating the need to
restructure the curriculum to suit the
CBC learners.

Most graduates who have a Teacher Service Commission (TSC) number, opt to work in the private sector, due to higher salaries compared to those offered by government schools. A few of them start their own schools or NGOs.

There is an urgent need to ensure that the SNE curriculum is implemented to the letter from pre-primary to the highest level.

There is an Increasing demand for SNE teachers as more children are requiring learning support.

This is because; many of the children requiring support can be identified in the pre-primary phase which is the stage recommended to begin early intervention therapy and have the most beneficial outcomes for the child as they grow.

All respondents agreed that the SNE curriculum as developed by the Kenya Institute of Curriculum Development (KICD) is not exhaustive. At the university level the SNE curriculum is autonomous.

This study established that many of the pre-primary schools in Kenya lack trained teachers in the area of autism.

### **Special Needs**

### **Insights and Qualifications**



There is an Increasing demand for SNE teachers as more children are requiring support.

KISE Requires applicants to have graduated with:-

B.Ed.

Bachelor of Education

**ECDE** 

Early Childhood
Development
Education

Or be a

### P1 Teacher

as a qualification to undertake a course at KISE

From Kenyatta University

8%

Graduates of Bachelor in Education

Specialised in Special Needs Education Graduants who join private sectors receive a minimum salary of:

30 to 35k



### SNE teacher process to certification:

### Step 1:

#### **Attain Educational Qualification**

There are various institutions that offer courses in Speech Therapy such as:

#### Kenya Institute of Special Education:

Diploma in Special needs education

#### Kenyatta University:

Bachelor of Education in Special Needs Education.

#### **Moi University:**

Bachelor of Education in Special Needs Education

### Step 2:

### Join a Professional Body

The professional body in charge of SNE professionals is the Teachers Service Commission (TSC).

### **Brain Drain**

### SNE teachers end up working abroad.

The respondent who is a lecturer at Kenyatta University observed that, lately, there have been some openings in the United States of America (USA) and many graduands have begun transiting to the USA.

Between 2022 and 2023, more than 10 students from Kenyatta university travelled to the USA on work visas to work in homes with children with autism as well as intellectual disability centres.





### **Minders:**

Trustworthy supervision is essential for children with autism both on the playground and in the home environment.

Nannies/minders receive special training and credentials to provide the necessary care and support.

They assist with daily activities and life skills, such as feeding, dressing, supervision, homework, transportation, while assisting to minimize dangerous activities such as elopement among others.



### **Stigma**

The public's knowledge about the causes of autism is not centred on medical discourse but rather on cultural beliefs leading to possible stigmatisation of autism.

Some parents could be in denial that their child is autistic with some becoming unsupportive of their children under the misconception that they are not smart or have behavioural issues.

There is a need to support awareness of autism and demystify commonly held myths; as well as also need to incorporate autistic adults in the narrative for first hand perspectives.



# Conclusion and Recommendations



The prevalence and impact of ASD in Kenya should be established. This data will be useful in allocating resources for diagnosis, and special needs education, as well as research and training of professionals to support children with ASD and their families.



The low number of SNE practitioners in Kenya compounded by the fact that many of them are based in urban centers creates a gap in the rural areas for children requiring special needs interventions.

This creates the need to package SNE courses as those with a promising future despite the heavy workload.

Additionally, there is a need for all pre-primary schools in Kenya to employ at least one teacher who has specialized in SNE. This will allow for early diagnosis and treatment of children with special needs.



Compared to other developed countries, the Kenyan curriculum on SNE is not exhaustive or comprehensive. The KICD develops curriculum for education institutes such as primary and secondary schools but not universities whose curriculum is autonomous. The need for SNE curriculum to be revised to suit the CBC curriculum currently being implemented in Kenya was also highlighted.



Special Needs Teachers and lecturers do not require any certifications to practice in Kenya.

They only need to have a TSC number to work in government institutions.

Advocating that all SNE practitioners obtain relevant certifications before they can practice in private and public sectors.



Parents access to occupational therapy for their autistic children is hampered by the high costs associated with occupational therapists coupled with the low number of OTs in Kenya.

Incorporating Occupational Therapy in the NHIF was suggested as one of the ways of making the costs of Occupational Therapy affordable to parents.



### Championing Brighter Tomorrows: Stand with Children with Autism and their Caregivers!



At BCB Foundation, we believe in the potential and brilliance of every child on the autism spectrum.

Today, we invite you to become a part of our uplifting community, where hope flourishes, and dreams take flight. By joining forces with us, you can be a beacon of hope for these extraordinary children, providing them with the tools and resources they need to thrive.

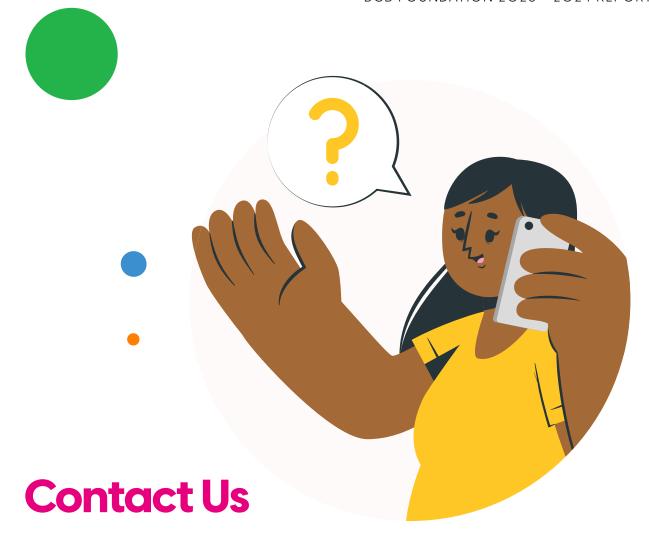
Together, let's create a world that celebrates uniqueness, embraces diversity, and nurtures compassion.

Step forward and help us paint a canvas of love, understanding, and endless possibilities. Your kindness will forever leave an indelible mark on the hearts of these families.

Together, we can inspire change, create a symphony of joy, and build a future where every child with autism is celebrated for their incredible brilliance.

Take action now and become a catalyst for a world filled with limitless love and potential!





Join BCB Foundation in our mission to support children with ASD and the ASD support community in Kenya. Together, we can create a more inclusive and supportive world for individuals on the autism spectrum.

If you involved in the ASD health care or education or are passionate about supporting the autism community, we invite you to join our cause. Together, we can make a positive difference in the lives of autistic children and their caregivers.

We are here to listen, assist, and connect. If you have any questions, suggestions, or would like to collaborate, please reach out to us.



Best Can Be



Best Can Be Foundation



@BestCanBeFdn







