



AUTISM AWARENESS CAMPAIGN CONCEPT NOTE

UNIVERSITY OF RWANDA, CENTER FOR MENTAL HEALTH AND HAND OF JOY

1. JUSTIFICATION

The Center for Mental Health, University of Rwanda, in collaboration with Hand of Joy and Autism Speaks are organizing an **Autism Awareness Campaign**. The Campaign has the principal focus of equipping parents, health professionals, and students in the College of Medicine and Health Sciences (future healthcare providers) with the basic knowledge and skills of Applied Behaviour Analysis (ABA), and an overview on the neuroscience of autism.

- ABA is a therapy which helps individuals with autism to manage their social interaction, gain new skills, confidence, and reinforce positive behaviours.
- An improved knowledge on the neuroscience of autism will assist professionals in the diagnosis of autism, which will improve the design and management of a care plan tailored to the need of the individual.

1.1. Why is an Autism Awareness Campaign significant?

The Autism Awareness Campaign is a priority of the **Center for Mental Health, University of Rwanda** to introduce relevant information and skills to support people affected by autism. The collaboration with **Hand of Joy** (the autism support organisation, registered in Rwanda in 2017) and **Autism Speaks** (the largest international advocacy community) is part of a long-term initiative to facilitate the introduction of the Global Autism Public Health Initiative to Rwanda. The Global Autism Public Health program will provide the necessary autism training and support in line with the United Nations Convention on the Rights of the Child and the Sustainable Development Goals, with its commitment to establish a world in which every child is able to develop their full potential with “no child left behind.”¹



1.2. Why is autism awareness information relevant?

Current global estimates state that about 1 in 160 children has an autism spectrum disorder (ASD). This estimate represents an average figure according to the World Health Organization, which states that some well-controlled studies reported findings that were higher and the prevalence from low- and middle-income countries is still unknown. Although epidemiological studies over the past 5 decades have indicated an increase in the prevalence of ASD, to what extent this may be the case is inconclusive not only because of the lack of research worldwide, but also due to the changing ASD diagnostic parameters with the implementation of the new DSM–5 case definition².

The United States Centers for Disease Control and Prevention, Autism and Developmental Disabilities Monitoring Network estimated in a period covering 2014 that 1 in 59 children aged 8 years from 11 sites across the United States has been identified with an autism spectrum disorder³. This is the largest active surveillance study to date highlighting that autism is an urgent public health concern as those affected cross all racial, ethnic, and socioeconomic groups. Autism spectrum disorders are about four times more likely to be diagnosed among boys than among girls, and this may be due to girls with autism presenting differently⁴. It is clear that much needs to be done to address the estimated prevalence of ASD worldwide to be able to support families affected by autism.

To help improve an understanding of autism the following awareness is vital: autism is a lifelong condition. Children with autism grow up to be adults with autism! Autism may go undetected depending on the severity of behaviours, the inability to interact socially, to communicate, and to manage sensory sensitivities. “Autism is often diagnosed alongside other conditions that fall into four groups: classical medical problems, such as epilepsy, gastrointestinal issues or sleep disorders; developmental diagnoses, such as intellectual disability or language delay; mental-health conditions, such as attention deficit hyperactivity disorder, obsessive-compulsive disorder or depression; and genetic conditions, including fragile X syndrome and tuberous



sclerosis complex”⁵. Those affected by autism and their families are at risk of being isolated and this has wider social and economic implications.

Early detection and intervention have been shown to make a difference in a child’s overall development and well-being, that may determine also the quality of their life in adulthood. Autism relevant care and support gives children more of a chance to acquire social skills and react with better understanding in emotionally challenging situations. An integrated training and management approach that includes parents/carers helps to improve understanding and to reduce the burden of care families experience due to their limited knowledge about autism and skills on how to care for their children⁶.

1.3. What can we learn from the Autism Awareness Campaign?

In the Rwandan context, the early detection of autism and an adequate intervention model needs priority and endorsement, as there is little awareness, limited clinical expertise, and inadequate educational services for those affected both in rural and urban areas. In addition, there is a need for scientific research studies to assess the prevalence and severity of autism spectrum disorders in Rwanda. This data would assist in informing government legislated policies and provide potential stakeholders, such as clinicians, educators, parent support groups, and representatives from the community with the necessary information for ongoing autism support.

2. THEME

‘Nothing for us, without us, is for us’

At the heart of the Autism Awareness Campaign is the **theme of inclusion** to be encouraged within schools and the community. “Inclusion is about offering the same activities to everyone, while providing support and services to accommodate people’s differences. Inclusive organizations actively reach out to people with disabilities and seek to understand and appreciate their differences, while fostering a sense of belonging”⁷.



3. AUTISM AWARENESS CAMPAIGN PLANNED ACTIVITIES

The Autism Awareness campaign will include the following activities:

- Seminar on Autism for healthcare students, parents and professionals.
- An autism awareness “walk and fun” day for the community.

3.1. Seminar on Autism

The seminar on autism will take place over two days. On one day, it will bring together healthcare students and on the other, parents and professionals. During the Autism Strategic meeting which took place in March 2019 a need to train the professionals and future healthcare providers (students) on intervention skills was emphasized, and this seminar will be initiated to address this need. The participants of the seminar will be trained on the basic knowledge and skills of Applied Behavior Therapy (ABA) and the neuroscience of autism. The seminar is scheduled for **23th and 24th October 2019**.

3.2. Awareness walk and fun day

The awareness walk and fun day will be organized with the intention of addressing the issue of stigma and isolation affecting those with autism and their families. The key message will be one of ‘**Nothing for us, without us, is for us.**’ This event will help support a Center [**KV: need to name center**] which cares for children with developmental delays, by providing them with the necessary equipment that they currently lack. It will be held on the **27th October 2019**.

4. AIMS AND SPECIFIC OBJECTIVES OF THE CAMPAIGN

The Autism Awareness campaign aims to promote early detection and intervention of autism in Rwanda, and to improve an awareness and understanding within the community.



Specific objectives

- Equip healthcare providers, university students and parents with basic skills and knowledge of ABA;
- Encourage the University of Rwanda to conduct autism research since there is no data on the prevalence of autism in the country;
- To promote early detection and prevention;
- To challenge the stigma associated with autism for those affected and their families;
- Raise awareness of autism in the wider community;
- Support a Center which cares for children with developmental delays.

5. EXPECTED OUTCOMES

- Increased public and professional awareness of autism;
- The establishment of a National Advisory Committee for Autism Support in Rwanda;
- To support a Center for children with developmental delays which is in need of equipment.

6. VENUE AND DATES

University of Rwanda–Remera Campus, October 23rd, 24th and 27th October 2019.

7. SPEAKERS:

Joelle Jinhee Park

[KV: need info]

Prof. Vincent SEZIBERA, BSc, MSc, PhD

Associate Professor of Psychology

Fulbright Visiting Scholar In-Residence, Chicago, IL, 2010-2011

Director Ag., Centre for Mental Health

College of Medicine and Health Sciences

University of Rwanda, Rwanda

Website: www.ur.ac.rw



Joanne Yu

[KV: need info]

Dr. Angelina Kakooza-Mwesige

Senior Lecturer and Paediatric Neurologist
Department of Paediatrics and Child Health
School of Medicine
Makarere University, Uganda
Chair of the Commission of African Affairs
of the International League against Epilepsy

8. WHY BE PART OF THIS CAMPAIGN?

- It is our moral responsibility to care for all members of our community.
- Autism may touch all of us.

9. For Further Information, please contact:

1. Prof. Vincent Sezibera
Tel: +250788771289
Email: vsezibera@gmail.com
2. Ms Chantal Waza - Director, HAND OF JOY
Tel 1: +256 772 988403 (WhatsApp)
Tel 2: +250 787 922 054
3. Ms. Joy Rurangwa - Founder, HAND OF JOY
Tel: +44 781 0424417 (WhatsApp)
Email: joy@hand-of-joy.org
4. Mrs Nelly Rurangwa (Local organizing team)
Tel: +250 784 212 727
E-mail : rurangwamulisanelly@gmail.com



REFERENCES

1. <https://www.unicef.org/eca/our-mandate-no-child-left-behind>
2. <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>
3. <https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm>
4. <https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>
5. <https://www.spectrumnews.org/news/conditions-accompany-autism-explained>
6. <https://myasdf.org/media-center/articles/early-intervention-makes-a-huge-difference-for-autistic-children/>
7. <https://www.autismspeaks.org/tool-kit-excerpt/inclusion-ensuring-access-everyone>