Autism Society of Kenya: Advocacy, sensitization and awareness campaigns

Autism Society of Kenya (ASK) is an NGO founded in Kenya in 2003 with the objectives to raise awareness about the existence of autism in the country, sensitize the communities and to lobby the Government of Kenya on issues about appropriate policies and acts regarding Autism Spectrum Disorder (ASD). Issues related to strategies were proposed to improve identification, diagnosis, management and support delivery for ASD affected individuals.

Autism is the term used to describe a group of complex neuro-developmental disorders. These disorders are characterized in varying degrees namely communication difficulties, social and behavioral challenges as well as repetitive behavior [1]. It is estimated that about 70 million people are affected by autism worldwide; making it a global health priority that requires increasing global awareness, services and research. It could also be estimated that 1 in 160 persons suffer from autism globally [2]. Such disorders adversely impact on quality of life of those affected as well as their families [1]. However, this burden is currently underestimated since prevalence of ASD in the African region, Kenya included and other low or middle income regions is not clear [2]. Inadequate diagnostic system for autism and low levels, of awareness both in the government systems and in the general community lead to poor records of national burden of the syndrome.

In the 14 years of existence of ASK and with its limited resources allocation, the society has covered much grounds in lobbying and advocacy at all levels especially to increase levels of awareness in the government system and the communities. However, considerable grounds must be covered to meet the set out objectives.

In the question of community awareness on autism, the Society has initiated a pilot programme at the mainstream public schools, namely City Primary School, Kasarani Primary School and St. Georges Primary School

in Nairobi County; Ruiru Primary School, Kiambu Township Primary School and Mukuyuini Primary School in Gatundu North in Kiambu County. The goal is to initiate autism learning programmes in other counties around the country, a process which is in slow progress mainly due to low resource allocation. However the Society does not tire to solicit for funds to further develop the programme despite the slow responses from the potential donors.

The Society envisage that there will be adult related programmes in which autism child benefiting from such school based autism education programmes would be followed up when he/she becomes a young adult. According to Autism Speak [1] about 50% of autism teenagers lose their autism services as they move to adult status. They are, however absorbed into the existing programs for adults. In Kenya, there are no such programmes catering for such transitional stages. Such young-adult autism patients are therefore left at the mercy of the public and may end up in the asylum because of misdiagnosis. Autism Society of Kenya is lobbying for programmes which will cater for autism patients in all stages of life.

The Society has successfully lobbied for implementation of all the United Nations Resolutions on Developmental Disorders specifically REB.133R1 on comprehensive and coordinated efforts for the management of ASD [3] by the Government of Kenya. We are in the process of forming parent's support groups for parents of children with Autism in order to train them on the appropriate skills to support their children and adults on the Autism Spectrum Disorder. The process is slow and it takes a long time for the families to see the benefits.

There is a major lack of knowledge and expertise in the management of autism in the country. The ASK is currently conducting massive campaigns in many parts of Kenya including remote areas of the country. For

example, our campaigns have penetrated the pastoralists' communities with some degree of success. The society has also reached the communities through mass media. For example, in June 2017 the ASK Director presented a one-to-one interview in one of vernacular Television Station (INORO). The presentation triggered massive response in which 19,325 telephone calls were made by people who claimed to have a family member with autism condition and they wanted to get more information on management, diagnosis and treatment. Such high figure of callers was a good indicator of the burden of autism in the communities.

Numerous challenges exist especially those related to coordination between stakeholder government ministries including the Ministry of Health, Ministry of Education and Ministry of Labour and Social Development. A great deal of lobbying is currently going on to achieve the kind of coordination that will be beneficial to the autism child but it requires much goodwill from the related different government departments and other stakeholders. Some of the gains from this type of lobbying is that the number of children diagnosed with autism in Kenya has continued to grow steadily because we have been able to reach more families with autism children all across Kenya. However, the need for specialist physicians cannot be overemphasized, an area which the Ministry of Health needs to focus on.

The United Nations Resolution 62/139 of 2007 declared April 2nd the World Autism Awareness Day [3]. Subsequent to the declaration, there has been a dramatic increase in autism awareness worldwide as well as additional resolutions related to autism and other developmental disorders. Examples of these include the United Nations General Assembly in 2012, World Health Assembly Executive Board in 2013, and the World Health Assembly Resolution on Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders (EBI.33.R1) adopted in Geneva in 2014 [3]. As the global community looks towards post-2015 developmental goals addressing disability priorities like autism, a strategic opportunity is emerging to ensure that all children thrive and reach their full developmental potential.

In 2014, Autism Speaks which is the World's Leading Autism Science and Advocacy organizations invited Autism Society of Kenya to become a part of one of its International Advocacy Leadership Networks. This is a worldwide Network of groups of organizations working together to enhance awareness, research and access to evidence based services for persons with the Autism Spectrum Disorders. The network is committed to sharing best practices of member organizations in addressing autism throughout the world. Autism Speaks has formed partnerships in more than 60 countries in five continents. Kenya enjoys the benefits of being in this group of Nations.

In an announcement made by the First Lady of Kenya Her Excellency Mrs. Margaret Kenyatta at the 7th Annual World Focus on Autism Forum Event hosted by Autism

Speaks in New York, (September, 2014), the office of Her Excellency the First Lady; in collaboration with Autism Society of Kenya acknowledged the Autism Speaks' Global Autism Public Health Initiative and its strategies. She recognized the needs of autism patients in our country and their families, made a commitment to invite Autism Speaks to visit Kenya to explore collaboration with Autism Society of Kenya and the Government of Kenya to help identify the best solutions and opportunities to deal with autism problems in the region. This process has since began and is in good process.

Autism Speaks Global Public Health (GAPH) initiative is an international advocacy program with an aim to help countries around the world to:

1. Enhance public and professional awareness of autism
2. Facilitate research including research that informs public health policy (e.g. prevalence)
3. Build capacity for autism services especially in early detection/intervention within each country.

Global Autism Public Health (GAPH) development and implementation are guided by a National Advisory Committee (NAC) which comprises the local stakeholders; international experts and Autism Speaks staff.

One of the objectives of the GAPH initiative is the national implementation of National Training programs: Country wide training programs in a range of health and education services that are tailored to the needs of children with autism. Together with World Health Organization Autism Speaks has developed Parent Skills Training Program for care givers /Parents of children with development disorders. Secondly, Andy Shih the vice President of Scientific Affairs/Autism Speaks has since visited Kenya and in collaboration with ASK, the Ministry of Health and other stake holders initiated the Skills Training Program.

The program targets parents of children aged 2-9 years with a developmental delay or disorders including ASD. The program is available now for pilot testing in various countries. While the program is based on the best available evidence and on the expert opinion of parents, researchers and professionals in the field, there is a need to demonstrate that the program is effective in improving competences of parents' and children's behavior and adaptive skills when implemented in a variety of different contexts. The program must also be integrated into the available community resources, meet the caregivers' needs, and be implementable in low-resource settings [4].

Several evidence reviews suggests that parents are able to learn the skills necessary to deliver therapies to their children with developmental disorders and that children benefit from these interventions [6, 7]. Further, there is evidence that non-specialists in community settings can effectively deliver parent training, noting that low intensity programs improve child developmental and behavioral outcomes and family wellbeing [8].

The WHO Mental Health Gap Action Programme (mhGAP) Intervention Guide for non-specialist service providers recommends parent training for management

of developmental disorders when available [5]. The World Organization Health and international partners, including Autism Speaks, a number of other academic institutions and professional organizations, recently initiated a collaborative project to make available a parent education program which can be delivered by none specialists providers, is evidence-based and that considers affordability and feasibility criteria of low-resource settings (e.g. group format, low- intensity and duration) [5 - 8]. Autism Society of Kenya has adopted this programme and the outcomes are promising. We are also in the process of developing clinical guidelines for the identification, diagnosis and management of children with Autism Spectrum ages 0 – 5 years. This process will go a long way in developing strategies for the education of the autism child in Kenya.

Autism Society of Kenya hopes that the Ministries of Health and the Ministry of Education will work together in collaboration and create a department which will cater for children with autism and other neurodevelopment disorders. This will produce high quality results and common challenges will be overcome.

References

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