

# THE STORY OF AACT

---

## **THE SILVER LINING IN THE CLOUD**

Sometimes it takes what seems to be a misfortune to show us the real blessings in our lives. Having sojourned through the phases of denial through to acceptance of a son's autism and finally being able not only to smile at the progress he has made but be able to reach out to others; to encourage them too to be accepting and seek help; and to reach out to the society at large is nucleus of the story of AACT and Autism in Ghana.

## **INSPIRATION IS MY SON WITH AUTISM**

My son, Nortey was diagnosed with autism at age 2 years, twenty-nine years ago in the United States of America. There was very little help at that time, even in the USA. I therefore had to become a stay at home mother since there were no early intervention programs. At 4years of age, my son was admitted to preschool and I volunteered in his school where I got a better understanding of autism.

When I returned to Ghana some fifteen years ago, searching for autism services for my son proved rather difficult. Nortey was sixteen years old with raging hormones, many challenging behaviors, ranging from self injurious behaviours (Sib's), aggression, insomnia, to mention a few. Sleep at night was a luxury (I was lucky if I got two (2) hours). What was I to do in a country where there were no services for children with autism? I felt like an outcast, dejected, alone, and petrified! I needed to find support and fast and there was none. I found some solace in church and felt compelled to tell whoever would listen to me talk about my son and autism. Thus began autism awareness in Ghana. Mind you not all pastors were welcoming, but I kept at it, asking for prayers and giving testimonies of how far God has brought my son and I. My sister was also spreading the word about autism and within a week she noticed a girl in her church that seemed to have autism. Mom denied her daughter's autism; only attributing child's condition to a lack of speech. Thankfully I met both mother and child and shared my story with her and amid tears she said she was also a returnee and felt very isolated and confused because of her child's autism. (The stigma one faces with autism in Ghana is horrifying.) By word of mouth I continued to talk to different people about autism and within months I got to know of a few families affected by the disorder. Thus began the autism families support group! Through the awareness campaigns, a few other families joined the support group. Autism did exist in Ghana and I was finding it!

I was fortunate to meet Mr. Mawusi, a special education teacher and a speech therapist. I hired him to help Nortey at home and the parents in the support group also expressed interest in the training Nortey was getting.

The Autism Awareness Care and Training (AACT) was thus birthed in 1998 in a small room at the back of my house. Fifteen years on, we work out of a house in Kokomlemle and currently, we operate with close to forty children, ranging from preschoolers to young adults.

## **AUTISM IN GHANA**

In Ghana having a child with autism is viewed by most as a curse on the family, or worse still the mother is labeled a witch; and mother and child are shunned by society. No one wants to know or care. Many people are not seeking the necessary help that they need; instead they are hiding these children at home, locking them up in their rooms, and denying them their basic human rights. Violent beatings are not uncommon! Family is so important in Ghanaian society, and yet, “families” are the biggest perpetrators of this ostracism, second only to the “church”; some churches just want to exorcise this “demon” away. The level of ignorance is unacceptable! It was from my anger over the situation that my project began. And until the awareness campaign began 15years ago autism was not recognized by the vast majority of the population and getting support was not even an option.

Sadly today, even among the well known disability groups in Ghana, autism as a disability is considered to be a *lesser disability*. The interventions in communication for autism include in many cases Picture exchange communication and sign language for those who are non-verbal and also to help those who cannot verbally express themselves properly. There are also sensory imbalances which make them candidates for a combination of visual, spatial and auditory modes of instruction and accommodations to facilitate functioning and inclusion. Autism affects the entire being and total functioning of the individual unlike the physical disabilities which affect only a particular part of the individual. Though some persons with autism may have intellectual disability others have normal or higher than normal IQs but because they are not properly understood, their intellect, skills and talents are left undeveloped.

Many children in mainstream schools who have autism but can somewhat express themselves suffer discrimination, teasing from peers and teachers and many do not even have desks and books as teachers claim they don't sit in the class let alone participate in activities.

## **AUTISM AWARENESS CARE AND TRAINING CENTRE**

The Autism Awareness Care and Training centre [AACT] encourages inclusion into mainstream education and society. Through our fifteen years of service we have assisted close to four hundred children and their families. AACT's training focuses on behavior management (which is the core of the entire training programme), functional academics, music and art therapy, speech and occupational therapy and life skills training. Resources to train these children simply aren't available for us here in Ghana. However, we are fortunate to receive speech/language and occupational therapy resources from international volunteers. We use local materials like the dry seed of the flamboyant tree as music shakers, Djembes drums for drumming to teach music and dance. Our staff works with the children on rhythms and many of them thrive on this activity. Since church is a vital part of Ghanaian lifestyle we spend Friday mornings in a modified worship service. Our staff members sing praise and worship songs with the children in English and the local language and teach the children about God through song and dance.

## **THE JOURNEY SO FAR AND THE LONG ROAD AHEAD**

Since the inception of AACT, resources have been very difficult to come by. My drive to start the centre was so strong that I had to dip (rather deeply) into our retirement savings (with my husband's encouragement) to get started. I needed to "AACT", so I did!!! Staffing is a struggle always since Autism is not recognized in Ghana and there are no courses or training provided; we have been learning through our many volunteers, the internet, and now, thanks to Awaawaa2, some of our teaching assistants have had the opportunity to be trained as classroom support staff. Awaawaa2 is a centre for communication disorders, started in 2006. AACT and Awaawaa2 have been collaborating on many fronts; doing awareness campaigns, seminars, parent training and student referrals, to mention a few. It has been a very rewarding relationship for students, parents and staff.

It has been 15 years since we began and we have traveled down some difficult paths, but still, we are doing our best to help as many children with autism as we can. What began with only two children has mushroomed into about 400 children walking through our doors. As you can imagine, for a parent caring for a child with autism 24 hours a day, plus being expected to cook and clean and watch over other siblings, is an exhausting, draining, wearisome job. In the same vein, many of our staff (facilitators and caregivers) find themselves exhausted at work and this makes teaching difficult. Working with one child with autism can be like working with ten regular children or more and so instruction is on a one-on-one basis. In very difficult situation one child may have two caregivers. We are striving to educate parents on the need for an autism caregiver to be solely for the child even in a home situation, but like everything, change is slow.

Keeping the center running has been difficult, but when organizations and individuals show interest in us we know we are on the right path. We are grateful for the support from our sponsors; and we appreciate the recognition shown us by local and international organizations. We have had to be innovative and creative in special education, so the child with autism can stand tall, feel and find their way in the world of confusion. Our biggest challenge has been in not giving up, but we've done it because the challenge in answering to a child in need is a deed necessary for the good of mankind.

## **ACHIEVEMENTS**

### **Facing autism with a smile**

Our greatest achievements have been with children who have made their way to mainstream schools through our early intervention programmes. Other remarkable achievements have been in the improved behaviors of children which have led to easier instruction and tremendous improvements in their ability learn.

### **Recognition**

Awards from Heartspring (a renowned disability centre in Wichita, Kansas, USA), the Ayeeko Excellence Foundation as well as the Esther Award; and citations from the then Ministry of Women and Children Affairs (MOWAC) are testimonials in recognition of our efforts.

Our dream is to see a society that is more inclusive and sensitive to the needs of persons with autism.

It is time to "AACT Now!"