A very brief history of the Autistic Society of T&T

The Autistic Society of Trinidad and Tobago (ASTT) was founded on 31st May 1990 and is a non-governmental organization that is first and foremost a parent support group for families of persons diagnosed with Autism Spectrum Disorders (ASD). Born out of this role, we began to offer services to children and adults with ASD, as well as training, as that was the type of support that parents were requesting.

ASTT was incorporated under the Companies Ordinance Chapter 31 Number 1 as a Company Limited by Guarantee on June 10th, 1991. ASTT is a registered charitable organization and a member of the Foundation for the Enhancement and Enrichment of Life (FEEL). ASTT is as a Non-Governmental Organization registered with the Ministry of the People and Social Development, Ministry of Community Development and the Civil Society Board. Annual General Meetings are held and accounts are audited. The last AGM was held on 22nd November, 2014. The Executive members are made up mainly of parents of individuals with autism and they are all volunteers.

VISION: The Autistic Society of Trinidad and Tobago will be the premier advocate and support organization to families affected by Autism Spectrum Disorders.

MISSION: To work together with families to help all individuals with Autism Spectrum Disorders to achieve their fullest potential through education, training and advocacy for affordable and appropriate services.

In July 2012, with funding from Republic Bank’s Power to Make a Difference Programme, a General Manager was employed to increase the efficiency of the organization and to carry out its strategic plan. The GM represents our group at different meetings to increase awareness of the needs of persons with autism. ASTT is currently represented by its GM on Advisory Council of the National Strategic Plan for Child Development of Trinidad and Tobago (2012 – 2016); as well as on the committee developing the terms of reference and logistics of the Autism Support Centre of Trinidad and Tobago. Both are initiatives of the Government, under the Ministry of Gender, Youth and Child Development.

Our headquarters, Autism Place, is located at LP#5 Ragoo Road, D’Abadie and we are affiliated with Therapeutic and Life Skills Centre, Pt. Fortin; Autism Tobago and The L.I.F.E. Centre, Petit Valley, so that we cover a wide cross section within Trinidad and Tobago.

To date, there are over 600 families registered with ASTT but according to prevalence statistics from overseas 1 child is diagnosed per 68 children (CDC, 2014). The United Nations recently stated that every country has an estimated 1% of persons with autism in its population and this would be about 13,000 in T&T. Even though Trinidad and Tobago does not have accurate statistics, it is alarming to consider that ASTT is serving less than .05% of the potential population of people with autism. Therefore the majority of families cannot access appropriate and affordable education for their children in their communities.

Our group extends services as funding is available. Our major sponsor is Republic Bank Ltd, through their Power to Make a Difference Fund. Presently we have adult groups, social/play groups for children, one to one therapy sessions (by appointment), and functional life skills training. We also have weekly music and art therapy sessions. A week long day therapy camp for children was started in August 2008 and has continued annually. In 2012, a day therapy camp for adults started in July. We began a 1 day per month respite care service to families who attend the Centre regularly, this has now been extended to offering daily respite to families who are in regular attendance at Autism Place. A few of our upcoming projects will be the provision of massage therapy, aqua therapy, and pet therapy.

When a child is diagnosed on the autism spectrum he/she requires 20 to 40 hours of therapy per week but the Autistic Society can offer up to 2 hours per week. Research studies have shown that the role of the family is vital in the development of a child with autism. Our parents are offered training to assist their child at home. We therefore utilize the parent as a co-therapist model. Many therapies e.g. speech therapy are very expensive and the parents who seek help from us are struggling financially and are also from very low economic groups in our society. These families are also trying to understand the very complex and challenging brain disorder and need more support in their individual communities.

We host experienced autism education specialists, behavioural therapists, speech and language pathologists and occupational therapists, from USA and Canada. They provide insight into the progress of treatment for ASD, consult with families and train our staff, as well as to provide workshops for parents, teachers, therapists, volunteers and other stakeholders. These are conducted equally across all locations to allow for the greatest participation possible and to raise awareness about ASD.

While autism awareness is on the rise, there is so much more to be done to increase autism acceptance in our country by all our citizens, including Government officials and politicians. Our children with autism need access to affordable and appropriate educational and therapeutic services. Education and training for persons with autism is very limited and very expensive but is important if they are to be adequately prepared for employment.

To date, our group does not receive a subvention from any Government ministry but has submitted proposals to 9 Ministries: Health, Education, Gender, Youth and Child Development, People and Social Development, Community Development, Local Government, Finance, Diversity and Social Integration, and Foreign Affairs.

ASTT needs at least $2.7 million per year to effectively run its centres; further our Point Fortin location requires a Centre as they rent at their current location.

We are also involved in increasing autism awareness throughout T&T. We have conducted workshops in Tobago and the President, the General Manager and other members of ASTT have given talks to a wide range of persons - educators on invitation of the Ministry of Education and the Teacher’s Union, nursing students, doctors on invitation of the UWI, PTA’s, private sector groups, other charitable organizations e.g. Rotary & Kiwanis Clubs.

**Awards:** ASTT has been the recipient of British Petroleum T&T’s Social and Community Awards having produced winning proposals. It included training projects and the production of a 20 minutes DVD “Autism: A Silver Lining” which won a PAHO/WHO media award for excellence as the best documentary in the area of health journalism in 2006 both nationally and regionally. In 2013, ASTT was the first NGO to receive the Service Provider of the Year award from Trinidad and Tobago Coalition of Service Industries (TTCSI).

**Social Events**: We are involved in a variety of social events including the annual PowerGen Sports & Fun Day, Family Days, Walkathons, Public Awareness Events and Christmas Treats.

**Outreach:** As a result of our efforts the following groups were formed: the Autism Association of Barbados, Autism Tobago, a parent group in Point Fortin and a South Support Group (no longer in operation due to death of Mrs. Copeland). A group is soon to start in St. Vincent by an educator who has been attending our annual workshops. We have also forged relationships with educators and carers in St Lucia.

**Training Initiatives:**

We have received funding from a variety of sources to conduct workshops in autism since 1999. Some overseas experts have included: Autism Education Specialist, Professor Kari Dunn Buron, her colleague Mrs. Joyce Santo of USA, as well as speech/language therapists, occupational therapists, personnel from the TIM Academy in USA (structured teaching), Dr. Dave Hewett (Intensive Interaction), Marilyn Moore (Speech Pathologist from Canada), Kimberly Lombard (Occupational Therapist), Jason Backes (Occupational Therapist) and Professor Brenda Smith Myles (world expert in Asperger’s Syndrome).

Last year, we launched a “3 tiered training initiative, providing certification in autism training - Introductory, Intermediate and Advanced certificates, endorsed by ASTT. To receive an introductory certificate, candidates completed a 20 hour programme and presented to a group in their community or school. There are also 10 advanced certificate candidates who were coaches to the introductory candidates. During the year individual workshops were held for the introductory certificate graduates to complete 5 workshops. They would then be eligible to join the Intermediate level, which will eventually lead to, after many hours of practice and theory attend the advanced course.

We also facilitated a six week module, six credit course in autism education for as part of the requirements for a Bachelor of Education degree in Special Education, organised by the Catholic Religious Education Development Institute (CREDI).

Our headquarters is located at #5 Ragoo Road, D’Abadie, on land donated to ASTT by the Trestrail Family.

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**EXECUTIVE MEMBERS 2014**

President – Mrs. Teresina Sieunarine (parent)  
Vice President – Ms. Gina Mohammed (parent, Point Fortin)  
Secretary – Mrs. Halena Kong Ting (parent)  
Treasurer – Mrs. Rose Anna Trestrail (parent)  
Public Relations Officer – Ms. Sarah Soo Hon (Art therapist)  
Floor Members: - Mr. Frederick Felix (CBT therapist ), Mr. Denanath Dalipram (parent), Mr. Eric Roberts (parent), Mrs. Catherine Simonet(parent)

General Manager – Ms. Nichol Alves