THE AUTISTIC SOCIETY OF TRINIDAD AND TOBAGO

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Introduction

In this paper I will outline some of the problems faced by families who have a child with an autism spectrum disorder and the role played by the Autistic Society of Trinidad and Tobago in assisting families to cope with this puzzling, heartbreaking and challenging neurobiological disorder. The prevalence of autism worldwide is high and now affects 1 child in 100 in the USA. In 2008 the United Nations designated every 2 April as world autism awareness day.

What is Autism?

Autism is defined by the Autism Society of America (ASA) as: “a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills. Both children and adults with autism typically show difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities. Autism is one of five disorders that falls under the umbrella of Pervasive Developmental Disorders (PDD), a category of neurological disorders characterized by ‘severe and pervasive impairment in several areas of development.’” (ASA 2004)

Research indicates that the following symptoms are the most commonly found characteristics of Autism. The child is:

- unable to coo by 12 months
- does not point or gesture by 12 months
- does not say single words by 16 months
- does not say 2 or more words by 24 months and
- has lost some social skills or language abilities.

Families must be able to accept that they have a child with a range of impairments including communication, sensory, socializing and behavioural problems. They also must realize that the child with autism is an individual who needs to be accepted for who they are. Autism does not define the individual. Like every human being, a person with autism is defined by the love and acceptance of other human beings and not by his/her impairments.

Dr. Sally M. Rogow (1998), a special educator in Canada writes in the article, “Hitler’s Unwanted Children” that “Vulnerability is not caused by disability; it is nurtured by every act whereby a human life is devalued.” She concluded by saying that Nazi victimization of vulnerable people was unique in its organization,
its mercilessness and its bureaucratic efficiency. It serves as a lasting reminder of the perils of making value judgments on human life, and of separating science from humanity.

Accepting and Valuing the Individual with Autism

Our parents must learn to not only accept their child with autism but value that child just as much as the “normally developing” child. This is a difficult task when our society continues to place more emphasis on the children who do well academically. Such children are regarded as “successful.” Devoted parents who are painfully trying to value their child with autism are certainly not helped in a society where academic achievement confers value and success. They, however, must turn to the same society for help.

Facing the Reality of a Lack of Services

When a parent learns that their child has autism, they will seek help in obtaining services and therapy for their child. Many also turn to the Autistic Society of Trinidad and Tobago (ASTT), a society of parents and caregivers who themselves feel the pain and devastation of having a child with autism. With the ASTT, parents can find some comfort, caring and empathy. However, other resources are needed. For example, parents also need a school, respite care, and residential care for their child or young person diagnosed with autism.

However, the Autistic Society has limited financial resources. As parents, we try to support families with the available resources received from many kind and generous individuals, groups and companies. ASTT services include parent-to-parent counselling, parent training, special educational/therapy sessions with their child, family get-togethers and public awareness programmes.

Caring for a Child with Autism: Some Problems Faced by Parents

There is much documented research indicating that parents of autistic children experience greater stress than parents of children with mental retardation and Down syndrome (Autism Society of America 2004). The unpredictable behavioural problems associated with autism can be a source of great embarrassment and worry to parents and caregivers. When a child or young person with autism has a meltdown, for example, in a public place, or goes up to a total stranger in a restaurant and takes the customer’s plate of food, it is the cause of great embarrassment. Parents suffer much anxiety when having to deal with regular epileptic seizures as many children with autism are also epileptic.

Reaction of the Society

Parents must face the unfavourable reaction of members of the society including members of their own family, friends, and neighbours. Stanley Hauerwas’ remarks are still relevant today when he wrote, in 1986, about parents of children with disabilities:

The difficulty comes not in accepting their own children, but in our society’s unwillingness to accept these children as part of our public lives. They often must learn to deal with the pained embarrassment, if not outright hostility, that results from bringing their children out in public. (Hauerwas 1986: 197)

For Trinidad and Tobago, a 2005 national study found that 46% of persons with disabilities
were cared for at home which was the largest single source of support for them compared to 2.6% who were in institutions (Kairi Consultants 2007).

If a survey was done among families in Trinidad and Tobago who care for their child/young person with autism it will probably be much higher. In the Autistic Society the majority of our members take care of their child/young person at home and so they are encouraged to take their child out with them and take information about autism to the restaurants, business places, banks, and other public places that they visit regularly. The message has to be sent to society at large.

**Dealing with Feelings of Guilt**

Confusion and pain is experienced by parents because they are uncertain what causes autism. Many feel that they may have somehow contributed to the child’s autism. It is also difficult for parents to adapt and learn to love a child who may not show warmth and affection towards them. This can lead to more feelings of guilt, as they find that it is not easy to love and care for an unlovable child. There is strain experienced among all family members and this can lead to the breakup of marriages and partnerships. Many parents also become clinically depressed which requires expert help. In this regard, Dr. Connie Anderson (2007) has noted that parents must get help if they, in turn, are to help their child with autism. Parent-training workshops teach parents skills to help them cope as well as to learn a variety of strategies that they can use at home to improve their child’s behaviour. These workshops have proven to be helpful in reducing stress.

In the USA, the data from the National Survey of Children with Special Health Care Needs indicated that, when compared with families that have children with other special emotional or physical needs, parents caring for autistic children faced a significantly greater financial burden. It is not only related to high fees for special therapy and medical costs, but the fact that many parents must either leave their jobs or cut back on their work schedule to care for their autistic child (Mozes 2008).

**Government Assistance**

Families also need affordable and appropriate therapies, schooling and medical services and social assistance. However, helping parents to find appropriate support from the different government ministries can be extremely frustrating.

At present, families must seek help from at least five (5) different government ministries in Trinidad and Tobago. It is my view that some other system has to be designed and that there should be community-based resources available to families. If these resources are easily available to families, they will feel less powerless and exhausted when faced with the formidable task to get government help.

Also, it is extremely frustrating for parents when they have to move their special child from school to school, from teacher to teacher, searching for a suitable school where the child can be taught, taking into consideration his/her different learning style. This is also true for teachers in special schools who need special training.

**Formation and Activities of the Autistic Society of Trinidad & Tobago**

In 1989, I got together with a few parents who had children diagnosed with autism. We
held regular meetings and shared our experiences and hopes. The group was formally established on the 31 May 1990. As more families joined, we realized that we were fulfilling a great social need and shared the dream that one day our children would be better understood and accepted in society. Alyson Bradley of New Zealand who has autism said: “I feel that life is a journey and we all have to learn to ride the storm, for some of us it can seem more like a tidal wave, but with every storm the sun eventually comes back out.” (Bradley 2009). Ms Bradley writes about her late diagnosis of autism and that her older son is also autistic at a website she manages called “Asperger’s Parallel Planet” (http://www.asplanet.info).

There are many separations and divorces among parents in ASTT as the strain of coping with a child who has so many challenges takes a toll on family life. There is a great need for professional counselling. We could only offer parent-to-parent counselling and this certainly has helped in some circumstances.

The Autistic Society of Trinidad and Tobago is now well-established. Our group is now 20 years old. We try to help families ride the waves in the storms of life. We try to give them hope for the future. Our activities include inviting guest speakers on a range of topics, parent training facilitated by autism specialists from overseas, networking with other disability groups and increasing autism awareness.

As it relates to our activities, these include:

- Facilitating support sessions and regular parent-training for families. Teachers and other interested persons can also join our sessions.
- Arranging regular early intervention sessions for individuals with autism. This includes educational and therapy sessions involving families.
- Inviting autism experts from overseas to help us learn the best practices used with individuals with autism.
- Networking with families and other disability groups, including autism groups overseas.
- Working together with government agencies, universities and other tertiary institutions locally and in the Caribbean to help increase awareness of autism and develop suitable training programmes.

Today there are some improvements, but the reality is that there are many children with autism who still cannot access appropriate educational training.

Seeking Autism Experts

As a group we realized that we could not find local experts in autism but had to seek help overseas if we were to get the appropriate help needed for our children with autism. Members of ASTT have been fortunate to be advised by two autism specialists, Kari Dunn Buron and Joyce Santo from Minnesota, USA, since 1998. One of them, Kari Dunn Buron, visited us in 1990 just as we were starting as a parent support group. The advice and training workshops they have conducted have helped ASTT to increase awareness of autism in Trinidad and Tobago as well as other islands in the Caribbean.

In 1998, with funding from the J.B. Fernandes Trust, ASTT was able to start weekly music therapy sessions with Mr. Michael
Gonzales, parent and special educator. As a result of the training by autism specialists we incorporated the educational sessions which continued to 2009.

ASTT now works mainly on early intervention therapies and parents continue the 1:1 work with their child at home. In November 2009 Mrs. Buron visited the programmes offered by ASTT and provided encouragement and praise for the work being carried out with limited resources and a small but dedicated staff. Thanks to Republic Bank Limited for partly funding the programmes in 2009.

Working with the Ministry of Social Development

In 2005 the Autistic Society marked its fifteenth anniversary by producing a four page full-colour glossy newsletter. Thanks to the Ministry of Social Development’s Disability Affairs Unit for agreeing to sponsor printing of the newsletter to help increase awareness of autism.

Our parent support group is happy to share information and network with other Non-Governmental Organisations and community groups.

In 2007 the Ministry of Social Development again sponsored an eight-page booklet, “The Autism Puzzle”, written for ASTT by Mrs. Suzy de Verteuil, Special Educator. This booklet is written for children to learn about the characteristics of children with autism so that the latter will be more accepted. It is a good book for all children to have at home and at school. The booklet was produced in collaboration with the Learning Is for Everyone (L.I.F.E) Centre, where Mrs. De Verteuil is the Administrative Director.

Collaborating with NGOs

Groups that ASTT collaborate with include:

- The Trinidad & Tobago Innovative Parenting Support group (TTIPS). For a few months in 2009 their staff used Autism Place, ASTT’s headquarters, for parent counselling and for parent workshops.

- The Caribbean Kids and Family Therapy Organisation (CKFTO). In August 2008 and 2009 we collaborated to organize a week long autism therapy camp for 25-30 children and young people at Autism Place. The Camp Director was Ms. Sara Stephens, an occupational therapist of CKFTO.

In November 2009 music therapy sessions started and in the near future ASTT will be starting regular occupational therapy sessions for children at Autism Place. The Ministry of Health and the Republic Bank’s “power to make a difference programme” are assisting financially to set up the space and buy the equipment required for this important therapy. ASTT has been a member of the Foundation for the Enhancement and Enrichment of Life (FEEL) for sixteen years, and, more recently, the Consortium of Disability Organisations, which advocates on behalf of different disability groups.

Two dentists from the School of Dentistry at the Eric Williams Medical Sciences Complex were invited as guest speakers at a general
meeting at Autism Place. The dental clinic for children and adults with special needs was opened to the public in October 2009 and despite being under staffed the service to the public is greatly appreciated. However, one of our families had to travel over two hours with her son from Point Fortin to Mount Hope to get help.

In July 2009 a very important presentation on autism and the role of the police was made to administrative members of the police service at Police Headquarters. Participants recommended that ASTT work on producing a database (with parents’ permission, of course) so that police stations would have records of persons with autism in the community. This is important because many children and young persons with autism may wander away from home or be badly treated by parents and persons in the community.

Growth of ASTT and Formation of Subsidiary Groups

During the formation of ASTT at the Kiwanis Library Building in St. Helena Village, Piarco, the Ghouralal and Mohammed families attended meetings regularly from Point Fortin. Today, they are still active members of ASTT. In 2003, Gina (Ghouralal) Mohammed and her family established a Centre in Point Fortin for young people to learn functional daily living skills and socialize as much as possible. It is called the “Therapeutic & Life Skills Centre.” This Centre employs Mr. Glendon Crepin, a young man with autism, to teach the students using craft, for example, origami (i.e. a form of visual/sculptural representation that is defined primarily by the folding of the medium-usually paper).

Male Caregivers Group

Male caregivers of ASTT held their first meeting recently to discuss relevant issues as fathers and brothers of persons with autism. They suggested that all parents could benefit from some legal advice on planning for the future of their child. A general meeting was arranged with a lawyer who gave invaluable advice to members.

Asperger’s Group

Other groups within ASTT had special meetings. For example, an Asperger’s group has been meeting regularly. They started a ‘social’ group among the young persons with Asperger’s syndrome, while their parents socialized or viewed a video to learn more about the condition.

South Support Group

In 2007, the support group in south Trinidad was established under the chairmanship of Mrs. Etheline Copeland, with weekly sessions starting in January 2009. They have been trying to get a suitable building to use for regular meetings. In August they held a successful family day for the first time.

Adult Social Group

In March 2009 a parent-driven adult social group was started with the encouragement of Kari Dunn Buron. A few families - The Johnsons, Millingtons, Daliprams, Ramcharans and Andersons - have formed one group. It is hoped that this will be a model to follow for future adult social groups.
Autism Association of Barbados

In 2005 the Autism Association of Barbados was established, mainly by parents and teachers who attended the Trinidad workshops conducted by Ms. Dunn Buron and Ms. Santo. The autism specialists have also conducted workshops in Barbados.

"Autism: A Silver Lining"

In 2006, with the help of British Petroleum Company’s (Trinidad and Tobago), “Spirit of Community Awards,” the ASTT obtained funding to make a 20-minutes autism awareness video. The Premier Video Company which produced the video was acclaimed winner of the Pan American Health Organisation award for excellence in the field of health journalism in the documentary category both locally and in the Caribbean. The title of the video is “Autism: A silver lining” and this is in keeping with the hope we are extending to all families who have learned that their child has autism. The silver lining refers to the acceptance of the family members, learning about the different therapies and strategies that can be used with the child to bring out his/her full potential. As Alyson Bradley (2009) said the sun will eventually come back out.

Autism Place

There are now well over three hundred and sixty (360+) families registered with ASTT. In 2007, a Centre was started in D’Abadie in east Trinidad on land donated to the Autistic Society by the Trestrail Family. At this Centre, Autism Place, our parent support group has continued the weekly early intervention therapy sessions started in 1998 with families. With the financial support from many individuals, groups and corporate sponsors, we have been able to pay tutors to work one-on-one with families so that they can learn the variety of methods that are used with autistic children and young persons. There are many children and young persons with autism who have benefitted from the sessions offered by ASTT. Some children have been able to get places in special schools, ordinary primary schools and those writing the SEA exams have secured places in secondary schools and Servol life centres and vocational schools. The consistent efforts of families and regular attendance at sessions organized by ASTT have helped to improve the quality of life of individuals with autism. Executive members of ASTT are trying to help parents to come out, meet others and become empowered as they also help others. “By contributing to the empowerment of others (persons with disabilities, etc.) one enters into relationships that are empowering to the person as well.” (Pedlar et al. 1999: 11).

ASTT Website

The ASTT website, www.autismtt.org, was set up with the help of Mr. Dexter Mahadeo of Trinidad, and Dr. Noel Winstanley of the UK when he accompanied his wife Caroline to Trinidad and Tobago. Caroline came to ASTT as a volunteer speech therapist and during her short stay met with many children in both islands who had never been able to see a speech therapist. We are hoping she can visit us again in 2010.

Establishing Links with Tertiary Institutions

In March and April 2009, Dr. Indra Mahabir, of My Goal Incorporated (USA), visited and assisted ASTT in setting up a meeting with personnel of the University of Trinidad & Tobago, in connection with incorporating a
module on autism in the Bachelor Degree programme for teachers. Autism Specialist, Ms. Kari Dunn Buron, who also attended that meeting, agreed to liaise with the coordinator of the programme. The ASTT executive has, over the years, tried to get other tertiary institutions to incorporate modules on autism for teachers as well as medical personnel.

Conclusion

To date, the Autistic Society has only been supporting approximately three hundred families. There are some families who belong to our parent support group who seek therapy for their children overseas. There may be at least ten thousand more families in our country if our prevalence is equal to that of the USA. There is still a lot of work to be done but we are very thankful for all donations of cash or kind we get. We could not have carried out the educational/therapy sessions without the help of our local facilitators. We thank the many persons in the community who volunteer their time with ASTT. Also, the executive committee who are all volunteers and parents, committed to improving the quality of life of persons with autism in Trinidad and Tobago.

Many parents are beginning to value their children and work with them so that they can lead more meaningful lives. It is a difficult road ahead but as parents we share the vision of a day when more easily accessible, affordable and appropriate educational opportunities and services for our children will be readily available.
References


