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The Tale of a Selfish Man

By Mohammed Ehasanul Hoque

Technology can significantly enrich the lives of individuals with special needs.



1999 was a memorable year. It was the year when I left Bangladesh to pursue higher education in the United States. It was also the same year that my mother gave birth to my younger brother, Eshteher. Despite the twenty years of age difference, I was excited to have a baby-brother. However, that excitement was short-lived as I had quickly come to learn that Eshteher suffered from a permanent mental disability known as Down Syndrome.

The first time I saw my brother, although I didn't intend to, some how I was hesitant to embrace him. Having a mentally disabled brother was not part of the perfect world that I wanted to live in. Being related to somebody with special needs is something that I believed was confined to only fictitious movies that you would watch and feel sorry about, little did I know.. I came back to my university campus with a confused state of mind. Not knowing what to do, I had conveniently decided to escape from the truth. Time went by. I never went back to Bangladesh. While my parents had visited USA a few times, I would find all the excuses to stay away as I was scared to face the reality. Running away from everything seemed like the easiest option.

One day my brother was running about on the playground and I was walking by. Not being able to balance himself properly at that moment, he fell and grabbed my leg. I looked at him. His face had a lot to say even though he wasn't capable of speaking then (he still can't today). I felt as if he was

whispering, “If you don't hold my hand, who will? I have no one, but you.” That look of helplessness on his face shattered me. I believe it was that very day when life changed for me, changing me into a different person with a different set of priorities. The negotiations with the top financial companies of Wall Street, who were willing to pay me a fortune to work for them, ended immediately. I realised what I really wanted was a career where I could spend all my energy looking forward to living in a perfect world along with my brother. This prompted me to explore the option of getting a PhD dedicated towards building technological solutions for kids with disabilities, utilising my background in engineering.

The reflection of my strong determination and motivation in my application was strong enough to get me admissions offers from some of the finest universities of USA. I accepted the offer from the Media Lab of Massachusetts Institute of Technology (MIT), Cambridge, USA, where our group focuses on building technologies for individuals with special needs.

At the Media Lab of MIT, we spend a significant amount of time and resources developing technologies towards a new future for individuals at the autism spectrum disorder-a future where individuals do not get lost in a social-setting, where treatment is devised based on real-world scenarios and the technology used is as comfortable as one's favourite clothing.

Autism is a brain disorder. The symptoms and signs may include disinterest in social communication, learning impairment, repetitive behaviours, and speech problems. For example, if an autistic person is busy lining up pencils on the table, s/he may just ignore everyone and everything around them until the pencils are lined up. Individuals with autism may express their joy by flapping their arms, or hurt themselves to indicate their frustration.

The reasons for autism still remain unknown. A few speculations, however, exist. Neuroscientists believe that due to the presence of excessive neurons, abnormal wiring patterns in certain places of human brain may be the cause.



Patience, understanding and respect are the best treatment for children with autism.

Since males are four times more likely to have autism than females, some feel that genes may have something to do with it. Virus can also be reason for autism. It has been suggested by a few studies that being exposed to rubella during the first three months of pregnancy also increases the possibility of conceiving a child with autism. There is a growing concern that toxins and pollution in the environment can also lead to autism.

Autism has become a national crisis for many countries like the USA, UK and many more. One out of every 166 kids is now born with autism in USA. In UK, it is even worse with a rate of 1 out of every 120. The US Government is spending 36 billion dollars every year to fight autism. In Bangladesh, autism is suspected to be very prevalent as well. However, no studies have been conducted to get a sense of how widespread autism is in Bangladesh. Current medical facilities are not equipped with adequate training or knowledge regarding early detection of such a disorder. It is needless to say that early detection could result in appropriate therapy from the very beginning, yielding treatment which would be more effective.

In 2007, I spent two months in Bangladesh exploring all the facilities that exist to help kids with mental and neural disorders. There exist multiple organisations, such as Autism Welfare Foundation (AWF), Society of Welfare for Intellectually Disabled (SWID) and Society for the Welfare of Autistic Children (SWAC) with the common theme of serving kids with disabilities. Despite the exemplary charitable efforts of the individuals running those organisations, the services available are yet to be comparable with western standards due to funding and other social constraints. Since the kids with mental and neural disorders have short attention span, they need to be personally monitored and nurtured; thus, entailing a desired ratio of 1:1 or 1:2 between the teachers and kids. This requires not only a huge amount of financial investment, but also a set of

people trained to work with kids with special needs. My research focuses on how can we use technology as assisting devices to minimise their constant dependence on humans on learning social and language skills. My long term vision is to expand my research to Bangladesh and make it available to everybody. Establishment of “Bangladesh Autism Research Institute (BARI)” is under-way to build a common platform of collaboration between the research organisations of USA and Bangladesh.

It is extremely difficult for parents to accept their child to be mentally challenged. This experience gets further aggravated with literally zero awareness that we have in our society towards this specific set of population. More often than not, it's the mother that gets blamed for conceiving a child with a mental disorder, and the kid gets labeled as “pagol” or crazy by the society. These parents are embarrassed to take their children to any social occasions resulting in no social life for either the parents or the children. After having a long day, parents often feel that beating them up is the easiest solution to get them to do something, which further aggravates the case. The kids with such disorders are not allowed to attend regular schools as other parents often object to that. Regular schools would not open additional sections for these kids, since it does not generate a lot of profit in return. The specialised schools for kids with disability do not have adequate resources to provide all the services. A few of the schools, which have standard education system, are only affordable by the privileged ones due to the high tuition fees, and as for the remaining kids- they get treated by village quacks, and eventually get pushed into a permanent handicapped life or slow death. Our goal should be to break out of this cycle and create an environment where the individuals with special needs can live a normal life with dignity and honor.

It is important to teach the general public about mental and neural disability since education is the only solution to acceptance. Being born with a mental or neural disorder is the same as being diagnosed with a disease. The best treatment that we can provide to them is our respect, recognition and patience. Our acceptance of individuals those suffering from such disorders and their families is tied with our awareness and knowledge. It is with education, cooperation and action that we can bring change to people's mindset about disabilities that are becoming increasingly prominent. Our creator has given most of us perfectly functioning mind and body that the individuals with special needs may not have been blessed with. It's only fair that that we use our abilities appropriately by being more tolerant towards the individuals who need our understanding the most.

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