

'The Extraordinaires'

NO CHILD SHALL BE LEFT BEHIND

Words | Clint Derric Egbert

What is human perfection? How can it be defined? Is anybody perfect?

These are questions that have remained unanswered ever since they were first asked – when that was, is unfathomable, much like the answers to them.

No two people are identical, each of us are different, in some way or another. Imperfection is what makes us human, and if and when scrutinised, each living organism will unquestionably display some form of defect. Therefore, being judgmental about someone else's blemishes would make us nothing less than hypocrites.

In some cases, however, there are people who have more evident forms of disability; they are unable to conceal their flaws like most of us do. These are children, born into this world with maybe a little less than what the typical human is expected to have, but at the same time, with a lot more of special abilities. They may appear to lack in comprehension, understanding and mobility, but to compensate for that they have what many of us don't have enough of – strapping determination, undying willpower and angelic humility. There are things in life that aren't as obvious, and sometimes we need to look a little closer. The following Y-rated attempts to shed light on the lives of the mentally and physically challenged children, and their families, in Oman, who are struggling from day-to-day in search of normalcy and a better life for their offsprings. Individuals that I like to call 'The Extraordinaires'.

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etting through hurdles in life are hard enough, sometime we encounter minor problems, and at times, too much for the heart and mind to take. But the thought of having to go through those troubles with further physical and mental shortcomings would be too excruciating to even imagine for the ordinary man. The human spirit, however, is an amazing thing; it tends to surge on to find a way around most of what life has to throw our way. The journey, though, is a difficult one, more so for these challenged beings. And who would know that better than, Aisha Baabood, currently working with Al-Amal Association, in charge of families with children that suffer from intellectual disabilities.

I had the pleasure of meeting with Aisha at the third annual Eunice Kennedy Shriver (EKS) Day that was commemorated in Oman by the Al-Amal Association for Intellectual Disability and Special Olympics, for the first time, recently.

Aisha is not only a driving force for children with disability, but is also a mother of a special needs child Omar. Her story is invigorating and captivating, her journey is heartening.

“I am a mother of a special needs child,” she tells me with dignity, “who has been trying to help families with special needs children wherever they may be. Thinking of my own situation, and the agony, helplessness and sorrow that I went through as a mother of a disabled child, makes me think of others who are poorer, illiterate and have nothing in terms of services. I began my work by volunteering to assist one of the associations of disabilities, thinking that that might be the first step to serve the community. Then, I was selected by families to be the ‘Head of the Family Support Group for Disabled Children’. I tried to identify parents’ needs by conducting a ‘Needs Analysis Questionnaire’ to help me understand their requirements and their problems. The questionnaire helped in setting goals and programmes to help parents defeat some of their troubles. Of course, at the beginning I couldn’t provide any financial assistance, however, I focused mainly on educating parents on how to treat their children.”

Aisha’s journey has been long and hard, and a fight that is only half fought yet. But the effort, already made by this lady, is enough to call it a battle of its own.



Aisha's story

"My son Omar was fine up until 11 months and 17 days. Three days before his birthday he got diarrhoea and began to catch fits. Doctors said it was generalised seizure and so he was sent to the PICU in the hospital. It was revealed that he was critically ill, but doctors seemed to be unsure about a diagnosis. I was told something new almost every day. One of them said my son was abnormal from birth but I failed to notice it, another told me he has brain tumour. Another theory was water in his brain. I listened patiently, but cried silently. I tried to be strong and prepare myself for the worst to come. So, after two months in the intensive care I was told my son won't live, and if does, he'll be useless, so it is better to pray to Allah to give me another child. So, I prayed to Allah and thanked him for his gift and asked to keep me strong to face my destiny. At the same time, my mother was hospitalised for kidney failure and she started her dialysis sessions. I was torn into pieces because my mother died unexpectedly while I was nursing my sick child. I can't even describe the remorse I felt. Yet, I had to accept the challenge of my life.

"So, the first thing I could think of was to travel abroad seeking for a second opinion. My husband and I decided to take to the nearest neighbouring country, which is UAE, because doctors warned us not to travel too much, as it could be very risky. Taking their advice, we drove, instead of flying. We met a neurologist who gave us the right diagnosis and suggested a plan to be followed by the local doctors. When we went back to Oman, doctors prescribed anti-epileptic medications, which is tricky because doctors can never tell which medicine will work best; it's trial and error. So, we kept trying till my son was on five antiepileptic medications. Realising that him taking so many medicines, and suffering from numerous serious side effects of them, could lead to his demise, I decided to take him to the 'Great Ormond Street Hospital' in London in UK, where we stayed for two months. There, for the first time, my husband and I felt that we and our baby were being taken care of. The doctors spent hours with us, explaining and informing us of the medical condition. We were sent to the top rehabilitation department where a team of physiotherapists, occupational and speech therapists, designed and shared with us my son's Comprehensive Rehabilitative Plan. In addition to that, I was taught some home exercises to do with Omar.

"When we got back to Oman I gave the new plan to the local neurologist to follow and his fits were controlled. However, I noticed that Omar was still behind in terms of speech, movement, perception, memory and even concentration, in addition to being hyperactive. So, I went to the SQU Library to search all books and encyclopaedias on medicine I could find, just to educate myself on my son's condition, I spent hours on the Internet and subscribed to various medical journals. I also registered in medical conferences or anything that had to do with intellectual disabilities. I learnt all medical terminologies in order to communicate with doctors in the medical language. One day, in 2009, I came across an article about the Adeli Suit therapy, which is a modification of a space suit called the 'Penguin Suit',

which was invented by the Russian Cosmonauts who used it to counter the effects of long-term weightlessness on the body while in space. The inner workings of the suit have elastic bands and pulleys that create artificial force against which the body works to help prevent muscle atrophy. The form-fitting suit, equipped with adjustable elastic bands, is designed to put the body in proper alignment. If a child does not have motor control, the suit acts as a restriction of those limbs' movements. Patients are then put through rigorous physical therapy for 30 days, six days per week. This rigorous therapy helps to 're-train' the brain, allowing it to understand and memorise signals from the correct movement of the muscles.

"So, after reading thoroughly, we decided to travel to Slovakia where the Biggest Adeli Suit Rehabilitation Center is located. We stayed there for two months, and in the first two weeks I noticed a dramatic improvement in my son. His muscle tone and coordination improved, and spasticity reduced. His speech improved too, along with his posture. I was given some instructions to follow after the treatment, but in order to fully complete the programme I was required to travel three times a year, or at least twice annually. Even though the costs involved were practically killing us, I still had to do it, because I really had no choice. We continued with the Adeli Suit for two years.

"In 2010, I attended a conference outside the country, where I met Danish Specialist, Lone Sorensen, the founder of the reflex therapy. I attended her lecture and workshop where I experienced the evaluation through the face, hands and feet. I was thrilled when the specialist told me about my illness, which is IBS. So, I started reading about it, and in 2011, I decided to travel with my family to Spain to take the 'Individual Parents Course', in which all family members train to apply the therapy on their children. Then guidelines, booklets and a DVD that contains a visual demonstration on how to apply the plan on the treatment, were given to us.

After two weeks of applying the therapy, I noticed huge progress in everything such as memory, speech, school performance, concentration, behaviour, social interaction and even motor skills."



Little knowledge is a dangerous thing; therefore, it is imperative, that in order to really understand things such as disorders and disability, one must educate themselves first. Aisha, in her determination to help her child made the effort to do just that. However, her drive for learning was fuelled, for all the wrong reasons. She tells me that due to the lack of cooperation she received from medical experts, she had no option but to delve into study herself if she wanted a better future for her child.

“Honestly, as a mother of a disabled child, I always feel that parents’ opinions are neglected. I went through a very painful experience with a few hospitals here, where my son was admitted in the Pediatric Intensive Care Unit. He was in a very critical condition and almost dying, according to doctors. I was told by the specialist that my son has 24-hours to live, and if he lived he would be ‘useless’. I was so shocked at what was being said to me that I almost fainted. Of course, the doctor didn’t bother to give me the full picture of my son’s medical condition; they didn’t want to answer any of my questions, or even share with me the findings of his tests. They appeared to have a strange negative attitude towards parents, something which I was supposed to accept, and take for granted, whatever their decision was to be, without negations and without questioning. They thought I was making trouble. Unfortunately, some doctors here, believe that parents are not educated enough for them to share anything that concerns their children’s medical conditions; this is what we are trying to change. If we can raise awareness and encourage doctors to be more sensitive, regarding patients needs, then half of the problems will be solved,” she exclaims.

On the flipside, Aisha claims that in order to counter this mistreatment of patients, and in order to provide refuge and hope to them and their families, there are other professionals who cater to the patients and their parents as if they were their own.

“The Family Support group initiated the Temprana Reflex therapy in Muscat. The groups provided free evaluation and treatment for a small group of poor disabled children - around 20 children. I was astonished with the results; Parents actually implemented the individual plans on each child. So, this response encouraged us to arrange visits to schools and hospitals to demonstrate live the Temprana Reflex therapy to special needs teachers and doctors. Even though teachers and parents were convinced about the therapy, doctors claimed that the therapy was not research-based, which is true to some extent. However, when I thought about it, I asked myself, ‘How much research have those doctors conducted, anyway?’ When a parent finds out about a harmless therapy that could make a big difference to these children’s lives, doctors oppose the idea. How can you research anything if you do not want to experiment it? That’s what science is about, isn’t it?”

“There are thousands of disabled children in the interior, and there are around 30 Wafa Centres that serves them. However, those centres lack various facilities”

Receiving treatment can be a rather expensive affair, even though it may be affordable for the fortunate few, there are families who are unable to bear the expenses and so choose to ignore the problem. To avoid this from happening, a swift and collective effort was required, which came in the form of what Aisha calls a ‘Decentralised Approach’. Together with her team she began visiting regions outside Muscat to investigate and offer services to families. They decided to offer free medical treatment to those who come from very limited financial backgrounds. Using the help of ministries and big companies, she managed to cover expenses for training parents on how to use one of the most effective complementary therapies known as Temprana Reflex Therapy. They succeeded at treating more than 217 disabled children, thanks to Specialist Lone Sorenson, Founder of the Temprana Reflex Therapy, and Director Manager of the International Institute of Reflex Therapy in Barcelona, Spain. The expenses touched a staggering 101,540 rials.

BELOW IS A DETAILED EXPENSE CHART PROVIDED TO Y BY AISHA:

Province	Date	No. Of Evaluated Cases	No. Of Group Course	No. Of Treatment Session	No. Short Individual Courses	Follow up Sessions	No of Intensive individual courses
Muscat	December 2011	47					
Sharqiya -North		53					
Muscat	February 2012	73		8			12
Muscat	March & April 2012	44	40	16	24	6	5
Total		217	40	22	24	6	17
No. Of sessions		367					
Expenses in Rials		17,360	32,000	1760	7680	240	42500
Total Expenses from December-2011 April 2012			101,540 Omani Rials				

Table (1): No. of disabled cases & total expenses

FOLLOWING SHOWS CASES THAT WERE TREATED AND EVALUATED BY SPECIALIST LONE SORENSEN IN OMAN FROM DECEMBER, 2011 TILL APRIL, 2012.

No of Cases evaluated by the Reflex Therapist in Oman						
S	Diagnose	Months & Province				
		December 2011 Muscat	December 2011 Sharqiya	February 2012 Muscat	March- April 2012 Muscat	
1	Autism	4	16	31	8	
2	Epilepsy	1	3	2	7	
3	Down's Syndrome	4	4	1		
4	Cerebral Palsy	26	20	6	12	
5	Migraine				1	
6	Developmental Delay	3	7	3		
7	Motor skill disorder	1			5	
8	Muscles atrophy				1	
9	Chromosomes disorders		2			
10	Brain atrophy	3	1		2	
11	Spina Bafida		1			
12	Cancer	1	1			
13	Trisomy18	1				
14	Infertility	2	1			
15	Metabolic Disorders	2	2			
16	Hormone Dysfunction	1	2			
17	Diabetics		1			
18	Hyperactivity	1	5			
19	Muscles spasticity	1	1	3		
20	Learning difficulties	1	2			
21	Stuttering	2				
22	Dyslexia		2			
23	Slip disc		1			
24	Speech delay		4			
25	IBS		1			
26	Neuro-motor Dysfunction	1	1			
27	Stroke brain	1				
28	Musculoskeletal Disease	1	2			
Total no.		47	73	50	37	
Total no. Of Evaluated Cases						217

Table (2) Evaluated & Treated Cases by the Specialist Lone Sorensen in Oman from December, 2011 till April, 2012.

WHAT IS TEMPRANA REFLEX THERAPY

Temprana Reflex Therapy is a method of computational modelling of electrical signals; a manual tool used in rehabilitation to simulate the entire body. The brain/central Nerve System functions using reflex areas and points on face, feet and hands, like using the keyboard of a computer. Like computers the brain processes are extremely fast and many simulations can be run in a short time, allowing great results, and quickly. The process stimulates the functional entity of interconnected neurons that influence each other - this process is also called 'Cybernetics Therapy', usually used to model complex relationships between inputs and outputs. It focuses on a 'Home Training Program for Parents' that lasts for three to four days, in which parents will be ready for hands-on treatment immediately. After training, therapists maintain contact with the family offering assessment; every three to six months parents need to schedule a follow-up consultation session, in case the specialist needs to do any adjustments to the treatment plan of the patient.

Aisha assures, "It is the only successful and comprehensive treatment I have ever tried on my disabled child. It is harmless and medicine free, and it treats all sorts of diseases. Also, it's not expensive, doesn't require special infrastructure like labs or medical equipment, it's easy to learn (possible to educate a professional therapist in a time span of one to six months), it improves cortex problems such as motor, mental, physiologic and metabolic dysfunctions; it can increase the body and brain ability to heal itself; the treatments are non-invasive and are safe, and does not rely on medication.

Temprana Reflex Therapy is brain-based concept used for analysing and treatment for brain damaged, stroke, lack of oxygen, Cerebral Palsy, brain intoxications, infections, genetic and non-genetic syndromes, metabolic disorders, neurologically disorders, physiological, psychological and mental disorders and learning and behaviour disorders.

RESULTS AND FINDINGS REPORTED BY PARENTS TO THE GROUP

No.	Diagnosis	Age (yrs)	Improvement observed after	Results
1	Metabolic dysfunction	15	8 weeks	Improvement in concentration, sleep & food improved , and school performance improved too
2	Epilepsy	9	2 weeks	Improvement in speech, motor skill, school performance, social skills, behaviour, food & sleep
3	Cerebral Palsy	17	6 weeks	Concentration and memory improved, less hyperactive
4	Cerebral Palsy	14	4 weeks	Improvement in, concentration, school performance, less hyperactive
5	Down's Syndrome	8	4 weeks	less hyperactive
6	Cerebral Palsy	6	1 week	Concentration and memory improved, less hyperactive
7	Cerebral Palsy	8	4 weeks	Concentration and memory improved, less hyperactive
8	Down's Syndrome	5	4 weeks	Sleep & food have improved
9	Epilepsy	13	2 weeks	Concentration and memory improved, less hyperactive
10	Muscles atrophy	22	3 weeks	Feeling sensation has improved
11	Cancer	44	6 weeks	Cancerous cells shrunk
12	Spina Bifida	19	8 weeks	Skin has improved
13	Muscles spasticity	10	2 weeks	Spasticity was reduced

Not understanding a situation, or being unable to help, is still understandable, but what Aisha reveals in her interview with Y is certain to send chills up your spine, like it did mine.

She says, “There are thousands of disabled children in the interior and there are around 30 Wafa Centres that serves them. However, those centres lack various facilities. Though the Ministry of Social Development is working on developing them, in terms of training the staff in special needs, it will still take quite a bit of time for these centres to improve their situation. I see children mistreated and beaten with sticks like animals by their families. I’ve witnessed it with my own eyes. I almost fainted and I couldn’t sleep for two weeks. The memory of that child dragged around and beaten is stuck in my mind and I don’t think I will ever forget that horrible scene. And I’m sure there are hundreds that are in similar situations.

“The main factor missing here is education. Education must be provided for families starting at schools to make them aware of the factors associated with disabilities. As a mother I have done my best to help my child overcome most of his problems and I really wish to help other parents to overcome their as well; I wish to change this tragedy into something more positive and productive. Instead of feeling petty, actions must be taken to save lives and help

others live with dignity. The intention of this article is to bring to light the desperate need for a change in general perception and understanding.

“It’s important to understand that disability is not the end of an individual but merely a challenge to be overcome, much like the other challenges we face everyday. Aisha’s goal is to see changes happen; to see services are provided to all disabled people all over Oman. If there are rehabilitation centres that can provide rehabilitative services as well as serve as educational resources for parents, then this will be a dream come true. Also, I wish that all disabled rights are activated to help them fulfil their basic needs in order to live with dignity - this way no child will be left behind.”

In order to pen this story and to learn more about these ‘unique’ individuals, I was urged to spend a little time at a disability centre here in Oman. After being around these children for hours, I suddenly began to feel rather uncomfortable. Unable to comprehend the reason for my awkwardness, I continued to observe them, as they observed me back with shy eyes. Then a thought occurred to me... was I the one feeling out of place? Was I the special outsider amidst their large numbers? Would I want to be judged or ignored?

