OSHWAL news e-magazine

First Ever E-Magazine | December 2011 | www.oshwal.org

Special Edition

Celebrating the 2011 International Day of the Disabled Person

in association with

ENABLING NETWORK
Embracing all Abilities

Contents

December 2011

Feature Articles

Editor's Note

Jai Jinendra!

Welcome to the **Oshwal News E-Magazine!**

This Special Edition E-Magazine is a joint collaboration by the Oshwal Media & Communication team and Enabling Network, to mark the **2011 International Day of the Disabled Person on 3rd December**.

In this **December 2011** edition of Oshwal News E-Magazine you will find articles about the International Day of the Disabled Person as well as about Enabling Network and a host of other articles exploring and raising awareness about disability within our Oshwal community.

We would also like to receive feedback on this E-Magazine. Please email us and tell us what is good and what can be improved in this E-Magazine. Also, please tell us if you would like to see this E-Magazine become a regular publication available for download from the Oshwal Website (www.oshwal.org) and if you have ideas about future E-magazine please feel free to email us.

The Oshwal Media & Communication team can be contacted by email on:

oshwalnews@oshwal.org

We would like to thank all contributors to this E-Magazine. Without your input and time and effort this E-Magazine would not have been possible.

Ashish Jayantilal Patani

OSHWAL NEWS E-MAGAZINE is the magazine of the OSHWAL ASSOCIATION OF THE U.K.
© : Oshwal Association of the U.K. | Reg. Office: Coopers Lane Road, Northaw, Herts. EN6 4DG
Registered in accordance with the Charities Act 1960 | Charity Reg. No. 267037

President’s Message

Tushar Jayantilal Shah

Jai Jinendra,

1981 marked the first International Year of the Disabled Person and since 1992 the 3rd of December has been designated by the United Nations as the International day of the Disabled Person. It is a pleasure to tell you that Oshwal Association of the UK fully supported the 1981 International Year of the Disabled Person and also supports the annual International Day of the Disabled Person.

However, we as a community have not always expressly stated this support and many within our community who are affected by disability and special needs feel neglected. Often we go ahead and plan events without ever really thinking about how we will encourage those with special needs to come; or what special provisions they need. To this end, it is a pleasure to introduce ENABLING NETWORK – a group formed to change perspectives, raise awareness and instil an understanding about disabilities (such as physical disability, learning difficulties, visual difficulties etc) to create a community of openness, tolerance and social inclusion at all levels (such as religious functions, social events, sports activities, etc).

If disability affects you or someone in your family, then I would encourage you to speak to the Enabling Network team and see how we can make things better for all Oshwals – regardless of their abilities or disabilities.

Tushar Jayantilal Shah

President, Oshwal Association of the UK

એનેબ્લીંગ નેટવર્કમાં સ્વાગત

જય જીનેન્દ્ર,

સૌથી પ્રથમ ઇન્ટરનેશનલ અપંગ વ્યકિત નો વર્ષ ૧૯૮૧માં હતો, અને ત્યારથી યુનાઇટેડ નેશને ૩ ડીસેમ્બરને ઇન્ટરનેશનલ અપંગ વ્યકિતનો દિવસ જાહેર કર્યો છે. તમને જણાવામાં ખુશી થાય છે કે ઓશવાળ એસાસીએશન ઓફ ધી યુકે એ ઇન્ટરનેશનલ અપંગ વ્યકિત નો વર્ષ ને ૧૯૮૧માં સાથ આપ્યો હતો અને દર વર્ષે ઇન્ટરનેશનલ અપંગ વ્યકિત ના દિવસને સાથ આપે છે.

પણ, આપણે એક સમાજ તરીકે આ સાથ દર્શાવ્યુ નથી અને ઘણાં આપણા સમાજના અપંગ વ્યકિતઓને લાગે છે કે આપણને તેમની ફીકર નથી. આપણે ઘણાં કાર્યક્રમો કરીએ છીએ પણ આપણે આ ખાસ વ્યકિતઓ ની જરૂરીઆત પણ જાણી નથી જેથી બધાં ભાગ ભજવી શકે. આજે મને ખુબ આનંદ થાય છે તમને એનેબ્લીંગ નેટવર્ક ની ઓળખાણ કરાવતા. તેમની દ્રષ્ટિ છે કે આપણા સમાજના વિચારો બદલવા, બધાને જાણકાર આપવી અને અપંગતા વિષે સમજણ આપવી (જેમકે શારિરીક અપંગતા, ભણવાની મુશ્કેલી, દ્રષ્ટીની મુશ્કેલી વગેરે) જેનાથી આપણા સમાજમાં બધા એક થઇને સાથે કામ કરે (જેમકે ધર્મની ઉજવણીમાં, સામાજીક કાર્યોમાં, રમતની પ્રવૃતિ, વગેરે).

જો તમને અથવા તમારા પરિવારમાં અપંગતા હોય, તો એનેબ્લીંગ નેટવર્કનો સંપર્ક કરો અને શકયતાને જોયા વિના આપણે ઓશવાળ સમાજ માટે શું કરી શકીએ તે જાણીએ.

તુશાર જયંતિલાલ શાહ

પ્રમુખ, ઓશવાળ એસોસીએશન ઓફ ધી યુકે

Editorial

On behalf of the Oshwal M&C Team

Jai Jinendra,

Welcome to the first ever **Oshwal News E-Magazine!**

This Special Edition E-Magazine is a joint collaboration by the Oshwal Media & Communication (M&C) team and Enabling Network, to mark the 2011 International Day of the Disabled Person on 3rd December.

A Voice for Disability Issues

As Urvina Shah explains in her article entitled "What is Enabling Network?" on page 4, disability within the Oshwal community is a very real and tangible issue, but at times is treated as a taboo issue. Many disabled members of our Oshwal Family have become disengaged and disenchanted with the wider Oshwal community. There are various reasons for this as was highlighted in a recent workshop held on disability issues at Oshwal Centre in September 2011.

To raise awareness of disability issues and address some of the concerns of the disabled members of our community, the OAUK Executive Committee formally established Enabling Network as a new committee in October 2011. This means that the disabled members of our community now have a direct voice within the Oshwal Association of the UK (OAUK) Executive Committee. This is a fantastic step forward for our community.

International Day of the Disabled Person

The annual observance of the International Day of Disabled Persons was proclaimed in 1992, by the United Nations General Assembly resolution 47/3. The observance of the Day aims to promote an understanding of disability issues and mobilize support for the dignity, rights and well-being of persons with disabilities. It also seeks to increase awareness of gains to be derived from the integration of persons with disabilities in every aspect of political, social, economic and cultural life.

The theme for 2011 was **"Together for a better world for all: Including persons with disabilities in development."**

As explained on the United Nations' website *"Persons with disabilities make up an estimated 15 per cent of the world's population. Almost one-fifth of the estimated global total of persons living with disabilities or between 110-190 million encounter significant difficulties. Furthermore, a quarter of the global population is directly affected by disability, as care-givers or family members.*

"Persons with disabilities encounter many disadvantages in their societies and are often subjected to stigma and discrimination. They remain largely marginalized, disproportionately poorer, frequently unemployed and have higher rates of mortality. Furthermore, they are largely excluded from civil and political processes and are overwhelmingly voiceless in matters that affect them and their society.

"Experience shows that when persons with disabilities are empowered to participate and lead the process of development, their entire community benefits as their involvement creates opportunities for everyone – with or without a disability. Including persons with disabilities and their communities in developmental efforts is important to advance the development agenda.

"Thus it is imperative that development efforts around the world include disability issues when determining policies, programmes, as well as allocating funds for developmental programmes and projects. Mainstreaming disability in development is a strategy for achieving equality for persons with disabilities…thereby contributing to the realization of a "society for all" in the twenty-first century."[1]

Thank you!

Thank you to all those who contributed, many of whom have shared very personal and somewhat difficult and emotional experiences they have had with disabilities. Without your contribution and courage this E-Magazine would not have been possible.

Ashish Jayantilal Patani

---

[1] Extract from the United Nations' website, www.un.org

What is Enabling Network?

by, Urvina Shah

According to The Papworth Trust, there are approximately 650 million disabled people worldwide, which is around 10% of the world's population. The UK is estimated to have 11 million disabled people, or approximately 17% of the population. The alarming truth is that within our own Oshwal Family we have no consistent and reliable information regarding disability. If we were to apply the national average of 17% to our community of 25,000 strong, this would mean approximately 4,250 people are likely to have some disability within our community.

The UK Government's vision is to ensure "by 2025, disabled people in Britain have full opportunities and choices to improve their quality of life and be respected and included as equal members of society." The question is what are we as a community doing on this important issue?

Aims of Enabling Network

With this in mind ENABLING NETWORK was formed to change perspectives, raise awareness and instil an understanding about disabilities (such as physical disability, learning difficulties, visual difficulties etc) to create a community of openness, tolerance and social inclusion at all levels (such as religious functions, social events, sports activities, etc).

EN's longer-term aims would be to see those less able or with learning difficulties be accepted as part of the Oshwal Family. EN has taken the first small steps towards tackling disability issues within our community, but we need your help if we are to achieve the longer-term aims. If disability affects you or someone you love then come and join the EN team. Help us improve the quality of life of those affected.

Enabling Network as a Committee

EN was established on 2nd October 2010 during the Oshwal Career & Development Fair, where it held a small workshop looking at disability issues.

From there, through the guidance of Nirmal Shah (North West Area Chairperson) and Chetan Shah (North West Area Secretary), EN was established as a sub-committee under North West Area.

Following on from the September 2011 workshop on disability issues, EN was formally established as a committee by the OAUK Executive Committee in October 2011.

EN Committee Members

EN has 14 committee members as follows, each of whom is affected directly or indirectly by disability.

- Anjali Gudhka
- Dhiraj Shah
- Kalpi Shah
- Rumit Shah
- Shama Shah
- Smita Shah
- Urvina Shah
- Ashish Patani
- Jitendra Malde
- Rahki Haria
- Sarita Shah
- Shital Shah
- Sweta Shah
- Ushma Shah

EN Members

Aside from EN Committee Members, any Oshwal member who is either directly or indirectly affected by disability or has specialist knowledge about disability matters can be a member of EN.

Membership of EN is **free** and **open** to any Oshwal member. To become a member please contact EN as per contact details below.

Membership of EN will help strengthen the voice about disability issues within our community further to bring about much needed changes to educate and raise awareness about the range of disability issues within our community and also to support the disabled members of our community to help them re-engage with the wider Oshwal community.

Working together we can make things better for all Oshwal members, irrespective of their abilities or disabilities.

EN Activities

Disability Survey

In order to better understand how disability affects Oshwal members, EN has launched the disability survey, which is a questionnaire, available for download from the Oshwal website (www.oshwal.org).

This will better help to understand the requirements of disabled members and help better events planning in the future. If disability affects you or someone in your family, please download and complete this questionnaire and send it to the EN team.

Workshop on Disability Issues

EN members held a workshop on Sunday 25th September 2011 at Oshwal Centre to discuss disability issues and brainstorm ideas of how we as a community can tackle these issues. See full article entitled “Workshop on Disability: A Report” on page X.

Oshwal Health Awareness Day

EN members had a stall at the recent Oshwal Health Awareness Day (OHAD) on 13 November 2011 at Oshwal Centre. Several EN members and volunteers gave their valuable time to raise awareness about a range of disability issues at the OHAD.

Sharing experiences

Many of the EN members have written articles about their personal experiences with disability and put together a list of useful website links which can be accessed on the disability page on the Oshwal Website (www.oshwal.org).

Furthermore, EN members have collaborated with the Oshwal Media & Communication team, to produce this first ever Oshwal News E-Magazine to celebrate the 2011 International Day of the Disabled Person.

Oshwal Lift Project

EN members are involved in the Oshwal Lift Project, which will see the installation of a lift facility for the physically challenged visitors at Oshwal Centre. To read more about this project, please see article entitled “Oshwal Lift Project” on page X.

More Information

EN team can be contacted as follows.

E-mail: en@oshwal.org

Mobile: 07981 130 471

Web: www.oshwal.org

Urvina Shah

Enabling Network

Visual Impairment

by, Rumit Pravinchand Shah

I have been on the Enabling Network Committee for the last one year since it started and I wish to share my experience on visual impairment.

There are large numbers of Visual impairments people can have including Retina Pigmentosa, Retina Detachment, Glaucoma, Muscular Degeneration, Cataract etc. I have had some of these conditions for the past 15 years. About 4 years ago, I had to stop driving since I could no longer meet the DVLA driving standard.

I work near Reading and live in London, so travelling to work daily without a car is an issue. Luckily, a number of other people from work also live in London and I am able to car share with them. On some occasions, I have used Network Rail to travel to work or stayed overnight in a Bed and Breakfast.

I am an Electrical Engineer and work for the National Grid Company. At work, I am in an office environment and spend most of my time on the computer. I have a slightly larger computer screen through the Display Screen Equipment (DSE) Assessment legislation.

Travelling to Oshwal Centre is also a challenge since there is no public transport for the final bit. I have mainly taken car lifts from friends and family for this and sometimes used a taxi. I usually don't like asking for lifts from other people and sometimes I decide not to go to the events rather than trying to arrange a lift.

Despite these hurdles, I have been very active in community events for the past 20 years with various organisations. Recently, I volunteered at the Oshwal North West Savantsari Bhojan, Oshwal MELA and Enabling Network Workshop. It was very encouraging to see a number of people with Visual Impairment taking part in these events. I am still able to participate in events and volunteer because my eyesight is fine at present, for normal activity in lighted environment.

Many people including myself do not carry a white stick or other equipment. Therefore, it can be difficult for others to realise we have a visual impairment. Other people will only know if we inform them.

Royal National Institute for Blind (RNIB) and Moorfields Eye Hospital are very good sources of information for people with visual impairment. You may also wish to meet other people within the community with visual impairment through Enabling Network. This may give us an opportunity to learn from each other and share experiences.

If you have knowledge or experience of visual impairment then please inform Enabling Network and help us develop the knowledge and services for the benefit of other people by engaging and submitting articles that may be relevant to increase awareness. Also please make full use of the services Enabling Network may provide.

More Information

Royal National Institute for Blind

www.rnib.org.uk

Moorfields Eye Hospital

www.moorfields.nhs.uk/Eyehealth

Enabling Network

Email: en@oshwal.org

What is it like in Inclusive Education?

by, Shital Shah

My name is Shital Shah, am 37 years old, and have Cerebral Palsy. My father is Mansukh Lakhamshi Shah and mother Niruben; sisters are Ushma and Priya Shah. I joined Enabling Network to bring about changes in the Oshwal Community. I would like, in particular, for Oshwal members to embrace the abilities of the physically challenged people, and not to ignore them. My vision is to help build a community where everybody is treated equally.

I had my primary education in Kenya up to the age of 8 years. In Kenya there were no facilities for people with disabilities, so my parents decided to emigrate to United Kingdom in 1982.

I had enrolled in Elmgrove First School from age of eight, the first disabled person in a 'normal school'. It was good to be with able-bodied children, though I did not feel different and the teachers were pleasant as well. I graduated from that school and was moving up to Elmgrove Middle school and the attitudes were the same. I encountered a hurdle at age ten years when the school's administration team had a meeting with my parents to discuss placing me in a special school. My parents, who are very outgoing, thought a move would disadvantage my learning; they had heated discussions with various authorities and succeeded in continuing my education in a mixed school with able bodied students with the help of an assistant.

This assistant helped me with just the physical tasks. After my time at this school, the school started taking on other disabled youngsters, who had physical difficulties.

After my time at Elmgrove, I was enrolled into Whitmore High School, again the first disabled person in a 'normal school'. Here, it was a lot more different, but some issues persisted. I made many friends here and was assisted to and from classes. After my first year, the authorities decided to build ramps and lifts to make it easier for me to go from one level to the next. I stayed at Whitmore High School for four years.

Then I started my three years study at Stanmore College. Again I was given a support assistant, for the physical tasks. After these three years I enrolled at University of Westminster. During my four years study, I did not need a support assistant because I would copy from my friend any notes that I needed. Examinations were conducted in a separate room, and I was provided with a scribe who wrote my answers.

After these seventeen years of education, I have attained a BSc Honours in Computer Science and a HND in Software Engineering.

What is Cerebral Palsy?

Cerebral palsy (CP) is an umbrella term encompassing a group of non-progressive, non-contagious motor conditions that cause physical disability in human development, chiefly in the various areas of body movement.

Cerebral palsy is caused by damage to the motor control centres of the developing brain and can occur during pregnancy, during childbirth or after birth up to about age three. Resulting limits in movement and posture cause activity limitation and are often accompanied by disturbances of sensation, depth perception and other sight-based perceptual problems, communication ability, impairments can also be found in cognition; and epilepsy is found in 1/3. CP, no matter what the type, is often accompanied by secondary musculoskeletal problems that arise as a result of the underlying etiology. Of the many types and subtypes of CP, none have a known cure.

Source: http://en.wikipedia.org/wiki/Cerebral_palsy

More Information

NHS Website

http://www.nhs.uk/conditions/cerebral-palsy

A Lawyer on Wheels

By, Sapna Shah

My name is Sapna Ratilal Shah and I have MUSCULAR ATROPHY, a condition in which I am physically challenged. I cannot walk therefore am in a wheelchair but despite this, I have achieved two degrees, PSYCHOLOGY (2006) at USIU and LAW (2009) at University of Nairobi. I was doing both degrees simultaneously but I stopped law as I was ill for two years and resumed in 2008.

Doing two degrees together was challenging, as I had to do assignments, projects and exams in both universities. Sometimes ten subjects in one semester was stressful but my determination and courage helped me complete my degrees. The other challenge was commuting from one university to another as both were far from each other. I currently study at Kenya School of Law to become an advocate.

Apart from studies, I have hobbies that relax me such as singing, playing the keyboard, going clubbing and socialising and reading articles and magazines. This year I have taken up a new challenge of being an inspirational/ motivational speaker and writing a book about my experiences in these twenty-five years. My life has not been perfect as I have always faced discrimination from people and many do not understand my situation but I ignore the negatives, as I know who I am and what I can do.

My parents have been my supporters throughout my life as they have sacrificed a lot of things to bring me where I am today and to make me an independent lady who can work and earn a living for herself. My brother and sister in law have always given me moral support and told me I can do the impossible as my brother always tells me that my brain muscles are sharp even though I cannot walk.

Alice (my maid) or second mother always helps me throughout my endeavours ever since I was two years old. She says she wants to see me go very far in life and one day I will become a judge. She helps me maintain my focus in my goals. She is with me in all my classes and assists me with all my activities such as going to the restroom and carrying me.

I have the most loving neighbours, relatives and friends who take care of me when my parents have gone out and they also cook for me. My teachers and classmates always help me at university to take tables from one class to another, to turn the pages of my books and other assistance that I need.

HIRAN, a friend and inspirer, whose words I will never forget in the future always told me “Never give up and be positive and you will achieve anything you wish to.” In this article I would like to thank him for giving me courage to start life again after I was ill, as I was very scared to do anything at that time.

My message to everyone is “Be determined and brave and take all difficult situations as challenges to succeed.” My message to society is “do not shun the disabled, they need support, caring and loving and they are no different to others.” Some disables’ I know are smarter and are very talented too.

Article by,

Sapna Shah

Never Give Up Hope

By, Parul Shah

My name is Parul Pravind Shah. I was born in London on the 21st October 1979 in North Middlesex Hospital. After a month of being born the doctors had discovered that I had a murmur (a hole in the heart) which then led me to have asthma at a later stage of my development. I stayed in London for several months and then my parents took me to Arusha in Tanzania. In November 1980 my brother Alkesh was born in Arusha.

On the 31st January 1981 after attending a lovely lunch that was hosted by an aunt and uncle in Moshi my mum, dad, aunt, granddad and I were returning back to Arusha. As we were returning back to Arusha a lorry came from the opposite direction and it collided into our car. My granddad passed away instantly and I was taken to Kilimanjaro Christian Medical Centre in Moshi. I suffered head injuries and had a small scar on my left hand. As the doctors tried to treat the injuries, I fell into a coma. I was in a coma for up to 3 or 4 days and the doctors felt there was little hope of survival and told my parents that they should keep praying to God for my survival. As the treatment at the Kilimanjaro Christian Medical Centre was not working, one of my uncles brought me to London and I was admitted to Great Ormond Street Hospital for Sick Children. My parents were still back in Arusha, Tanzania, so my aunt and uncle cared for me. Due to the extent of my injuries, I had to have a few operations at Great Ormond Street Hospital for Sick Children. In conjunction with this, I also attended North Middlesex Hospital for eye treatment that I had injured in the accident. For several months I had to wear an eye patch on the right eye. The injuries that I suffered from the accident were Visual Impairment, Speech Impairment and Right Facial Palsy.

In 1982 I had to make several visits to Great Ormond Street Hospital for Sick Children to assess the progress of my treatment and in 1983 I received squint surgery at North Middlesex Hospital in London.

In June 1983 my parents and my brother arrived in the UK. From 1984 or 1985 until 2000, I attended schooling institutions from primary to secondary school. My educational life took longer than normal to finish due to being in hospital to undergo some major operations such as eye surgery, facial grafts, treatment for facial palsy and closure of my hole in my heart. During my schooling years, I was often bullied but also received encouragement from certain teachers, friends and my parents, which enabled me to carry on.

Despite these set backs, I completed 8 GCSE's and attained a GNVQ in Leisure and Tourism at advanced level.

Whilst I was at secondary school, I gained work experience in a variety of places where I took on various roles and duties. Between the years of 1995-2000, I was a library assistant, a reprographics assistant, a secretary and a chef. Each job taught me something new or I taught myself which increased my confidence and enabled me to become independent. Some of the things that I taught myself were how to use the Risograph photocopier and how to use the word application on the computer. Examples of skills I gained through my work experience were training younger pupils to become librarians, cataloguing books, administrative tasks, organisation skills, communication skills, presentation skills and food knowledge.

Between May 2001 and October 2001, I attended Enfield Training Services where I did an NVQ Level 1 in Administration and Prep for Work.

Then in October 2001 I had started attending Community Systems where I did Business Administration using Information Technology. I also achieved my European Computer Driving Licence through the completion of several modules which included: Basic concepts of Information Technology, Using a computer and Managing Files, Word Processing, Databases, PowerPoint Presentations, Internet and E-Mail, Windows' 98 and Office 97. This course had lasted for 6 months. As well as doing these modules I had to look for a job. I wrote many letters to many companies and I also looked in the newspapers as well. But unfortunately because I had little experience, it was hard to find a job.

In February 2003, I underwent another eye operation to correct a squint and eyelid in my right eye.

In September 2005 I started voluntary work as a teaching assistant at Bowes Primary School. I helped children read and spell, carried out Library duties and administrative tasks and took charge of the stocktaking.

Also each year I did a presentation to explain what Diwali was and why we celebrated it to a Year 3 class. As well as explaining the reason behind it I also showed the class the different types of Rangoli patterns that we do during the festival.

Between October 2009 and May 2010, I carried out more voluntary work at Garfield Primary School where I helped out in the school office with photocopying, shredding old documents, tidying the stock cupboard, stamping the school address in the library books and laminating the work for the class teachers.

In November 2010 I started volunteering at Raa (UK) Limited for a couple of days a week. The Managing Director was impressed with the work that I was doing and in June 2011 I had started a part time job as an Administrator. As well as having a part-time job I am still carrying on with my voluntary work at Bowes Primary School every Tuesdays.

~ Never Give up Hope ~

My Manager encouraged me to carry on with my voluntary work as well and I joined a group called the Sansaar group.

Even though I didn't have many friends during my education period, throughout my life I have met so many people who have come and gone and I would like to call them my friends and family.

I try to keep in touch with the friends that I did make over the years through Facebook.

In my free time I like to watch TV, listen to both Indian and English Music, going to the cinema, reading and doing puzzles.

I have travelled with my parents to Kenya and India mainly to visit my relatives but I have also gone to see the different temples and the forts that the country has to offer.

I have a lot of support from my cousins, aunts and uncles who I meet up with now and then at family occasions, meals together and by going to see a play or a film so that I can keep in touch with them.

In order to carry on regardless of the difficulties faced, I have to use my inner strength and resources, which I have developed over time through sheer determination. None of this would have been possible without the encouragement, praise and support from family, friends, my boss, teachers and most of all my parents. All of this has given me the confidence, will power and independence to tackle any challenge by giving it my best shot and not giving up.

In spite of what has happened to me in the past I can still carry on enjoying the life that has been given to me because no one knows what the future has in store. Even though I still get upset about what happened to me, I can carry on living my life and learning new things, meeting new friends and being more active. Life is too short so I always try to move forward rather than backwards.

So my message to you is 'NEVER GIVE UP HOPE'. After all, what have you got to lose!

Article by,

Parul Shah

Who looks after Carers?

by, Varsha Dodhia

Carers – members of the family and friends who care for people with disability and long term conditions

> ***"When dad took ill it was a complete shock to our family but we just had to manage and get on with it," explained Jayshree. "I was a carer for seven years before I ever knew about support or services available for Carers – it was a very demanding and hard journey".***

Carers take on a lot of responsibility and at times it can be a lonely place, with little support and professional training. Husband and wife often cannot go out at the same time as one of them needs to be at home. There are examples of young people aged 8 or 10 who take on caring roles for their parents. Here are some facts about Carers which many people do not know:

> ***1 in 8 adults in the UK (around six million people) are carers.***

- If we estimate that there are 25,000 Oshwals in the UK and we have more than 4,000 people with disability and/or long term condition then we must have over 3,000 people who can be called Carers. That is a significant number of people.
- A lot of our community Carers are not recognised on any official lists within the Local Authority where they live. As a result, they do not get the support services which Carers desperately need and can benefit from.

> ***Carers save the economy £119 billion per year, an average of £18,473 per carer.***

- Over 3 million people juggle care with work. However the significant demands of caring mean that 1 in 5 carers are forced to give up work altogether.
- The main carer's benefit is £55.55 per week for a minimum of 35 hours, equivalent to £1.58 per hour - far short of the national minimum wage of £5.93 per hour (2011-2012 figures).

Carers UK, a charity providing support in this area explains: *"The number of people providing round the clock care has increased by 50% in recent years. The social care system is in crisis and severely underfunded. This has devastating consequences for older and disabled people and a knock-on effect for carers who have no option but to fill the gap. Many families are outside the social care system altogether and get no help whatsoever and others face a constant battle for the most meagre of services. Carers are paying the price with their health, income and careers".*

In London, the Census data shows that the South Asian community has the largest percentage of Black Asian and Minority Ethnic Carers, Indian Carers being the highest percentage among these groups. For us, caring is a natural role in our lives, and we need to understand the system and support services that are available to us as individuals and as a community.

Among the London Boroughs

Barnet has a good Carers centre in North Finchley. Brent has a centre in Wembley, Harrow a centre in North Harrow and Hillingdon in Uxbridge. All Carers should have some training regarding first aid, lifting and handling, health and safety. Carers also need advice on managing their own finances, understanding how best to help the person they care for, sometimes they may need advocacy service if they are facing difficulties in getting what they need.

Do you know that as a Carer one should have their own Carers Assessment?

Adult Carers who are providing in excess of 10 hours of care per week for a person aged 18 or over have a right to a carer's assessment. Young people caring for an adult family member will receive an assessment even if they are caring for less than 10 hours per week. A carer's assessment is a set of questions that will identify how caring impacts your life .It helps to work out what support might be offered to you. A carer's assessment can be carried out even when the person you care for refuses help or an assessment for themselves.

What are the barriers that Carers face?

Carers often feel they have a duty for caring and should not complain. Sometimes they struggle on their own and their own health suffers and sometimes they face isolation. Carers who look after people with learning disability or mental health condition or dementia sometimes find it hard to talk to others about their caring role. For older Carers, language is often a barrier and lack of knowledge about whom to approach and how they can ask for help.

Breaks from their caring role make a huge difference in helping carers to continue – it is not a luxury – for a carer it is essential to their well-being and ability to carry on. And, if they are unable to carry on caring, there will potentially be enormous care costs.

If you're the main carer of the person you're looking after, one way you can look after yourself is by taking an occasional break from your caring responsibilities this is known as respite care. Carers can use respite care to take a holiday or a break, or time off if they're ill themselves. You might take a break for a week, one morning each week, or just occasionally.

Respite care can include:

- Day-respite services, where someone will come into your home during the day to care for the person you look after, giving you a chance to go shopping, meet friends or have time for yourself.
- Residential care in a home for a short period of time
- Offer companionship and conversation thereby stimulate mental awareness – sitting service
- Help with travel arrangements for hospital appointments and/or assessments
- Help with supported living
- Accompanying to lunch or dinner or activities

Officials often see all Asian communities as homogenous and yet they are extremely diverse.

There are misconceptions about extended family support that may not exist; bulk of the caring role is on one or two people in the family. "They look after their own" is often echoed in discussions about providing services.

A direct result of not coming forward and asking for help is that there are few services developed that suit our cultural needs.

A way forward

We need to develop a stronger voice and help our community Carers with support and advice. Recent changes in the way Social Services provide care by making it more suited to the individual called "Personalisation or Personal Budgets". Local Authorities are now being encouraged to provide individual budgets for people with care needs and for carers. This means that you should be offered choice in the way that services are provided, and may be able to use the funding to organise services yourself. This means people who are disabled or suffering from long term conditions can plan and have a much bigger say in the type of care they receive.

We have a wealth of knowledge as well as community members who have had to manage the system. If we can harness their expertise for the benefit of all Carers we would be in a much better position to influence other services that are available.

Article by,

Varsha Dodhia

Barnet Asian Carers Group

by, Suresh P. Shah

After much pressure from Asian community London Borough of Barnet decided to start day centres for Asian residents. Initially a room was allocated within an existing day centre for Asian residents and the numbers were limited. The services offered were not adequate for our needs.

In early 90's a few of us got together to form Barnet Asian Carers Group (BACG). When BACG was formed initially the activities were primarily focussed on increasing awareness for Asian residents.

The initial hurdle was that members were not prepared to come to day centres. Some preferred to stay alone at home and were reluctant to join a day centre. During a quick survey we found the main reasons were:

- A perception that people would talk about them going to a day centre
- Children unhappy and also felt guilty if someone talked about them
- Some parents were not allowed to leave home for such an event
- Lot of distrust about services

However as our group became more formalised we started to tackle the shortcomings in services being offered.

Campaigns

The group was involved with following campaigns:

- To ensure one good vegetarian meal was provided to member's coming to the day centre as well as providing a 'meals on wheels' service for house bound elderly people
- To ensure continuation of Asian day centres when Barnet announced cuts in budget.
- To ensure more beds were provided where Asian residence facility was available
- To request more respite care beds for Asians.

In a short time, carers of Asian members visiting all day centres in Barnet came within the group. This assisted in direct negotiations with Barnet on some issues.

Support

For carers the group provided the following support:

- Training sessions were held to teach how to handle disabled human body
- Training sessions on relaxation techniques
- Training on how to tackle pressure of looking after disabled or old members of family
- Information on services available in Barnet
- Counselling service
- Diwali get together

The group was recognised by Barnet and listed in their directory.

The group continued for several years but sadly due to lack of support was wound up. During its existence lots of assistance was given by Nila Patel, Ramnik Shah and Saroj Parekh.

Finally running such groups brings a lot of satisfaction as it adds value to people in need. Such carers group can be started easily and once the aims are finalised then it is best to affiliate with the local or national carer's group. A contact also needs to be maintained with local authority social department. Many established charities are always willing to assist. Sky is the limit of what the group wishes to achieve.

Article by,

Suresh P. Shah

Obsessive Compulsive Disorder

by, Chandu Shah

A Personal Experience

My wife Kanta and I act as carers to our son Deepan, who was diagnosed with Obsessive-Compulsive Disorder (OCD) in 1989. He was 22 years old. Deepan was a very bright student and achieved a BSc (Hons) in Finance at the London School of Economics.

He was on his way to becoming a chartered accountant, but during final year at the university he began to have problems. A friend who is a Consultant in America noticed something was wrong with Deepan's behaviour during our holidays in USA. He suggested that we get medical advice in UK and any help needed.

At the beginning of his illness, people and community members used the words like ‘pagal’ and ‘ganda’. We did not know whom, besides the GP, we should speak to and get help from or guidance, i.e organisations / local council / Care Centres / our own community.

In fact, when we contacted Oshwal Welfare section, they had no information available at that time.

Today Deepan is still a very smart person, but he is deeply affected by his mental illness. He is terrified of germs and does not leave his flat except for two days when he goes to the Day Care centre. Kanta and I dedicate over 100 hours a week between us to his care, house keeping, shopping, cooking etc. plus transporting to day care centre twice weekly and for all his medical appointments.

My son has a severe illness, but he is still my son and the wonderful intelligent person he has always been.

I am glad to see Enabling Network being formed within the Oshwal Community who will be able to provide a signpost and guide all the community members suffering from various disabilities.

About OCD

Obsessive–Compulsive Disorder (OCD) is a serious anxiety-related condition. It has 3 main parts:

- Thoughts that make you anxious (obsessions)- thoughts, worry, distressing pictures in the mind, doubts, the need for perfection and ruminations that will not go away.
- The anxiety you feel (emotions)- tense, anxious, fearful, guilty, disgusted or depressed. You feel better if you carry out your compulsive behaviour, or ritual - but it doesn't last long.
- The things you do to reduce your anxiety (compulsions)- correcting obsessional thoughts, carrying out rituals, checking and rechecking, avoidance, hoarding and the need for reassurance from others that all is well.

OCD sufferers may achieve diagnosis and treatment late partly due to a lack of understanding by the individual and health professionals and partly because of the feeling of embarrassment, guilt and sometimes even shame associated with what is often called the ‘secret illness’.

It’s important to remember that severity of OCD differs markedly between people but each person’s distress is very real. People with OCD are not ‘mad’ or dangerous and do not carry out their unpleasant thoughts. Most people with OCD know that their thoughts are excessive or irrational but the anxiety they feel makes the thoughts difficult to ignore.

The cause of OCD is much debated but it is likely to result from a combination of factors. In addition to this, the cause for one person may differ from that for another. OCD can run in families and, in some cases, may be associated with an underlying biochemical imbalance in the brain.

Treatment

OCD is indeed a chronic, but also a very treatable medical condition. Most people can learn to stop performing their compulsive rituals and to decrease the intensity of their obsessional thoughts through Cognitive Behavioural Therapy (CBT). CBT is a form of talking therapy that focuses on the problems a person has in the here and now and helps them explore and understand alternative ways of thinking (the cognitive approach) and to challenge their beliefs through behavioural exercises.

For some people a combination of CBT and medication can be effective. Medication may reduce the anxiety enough for a person to start, and eventually succeed in therapy.

Support and Help

There are various organisations and charities that provide support and information such as MIND, OCD ACTION, OCD-TODAY AND OCD-UK. The royal college of psychiatrists also has information leaflets on OCD.

A person with OCD can learn to manage symptoms so that they won’t interfere with daily functioning. This allows them to regain a much-improved quality of life, but it is also possible, with the right support and treatment to achieve a complete recovery from OCD. Fortunately, the medical profession is slowly starting to understand and identify OCD symptoms much more effectively, resulting in an improvement in treatment; however, it does still depend on which part of the country you may live in. OCD sufferers and their families need to seek help and support and know that the help is out there and they are not alone.

Riks' Story

Contributed by, Anthony Nolan

I was first diagnosed with Acute Myeloid Leukemia(AML) in 2009; prior to the diagnosis I had always considered myself to be very fit and active, a regular gym goer and football player. The diagnosis was nothing short of devastating not just for me but my family. We went from a relatively busy “normal” life into a world of uncertainty about the future.I was thrown into five months of intensive chemotherapy followed by months of recovery, prior to this I had never spent even a day in hospital.

Following treatment I eventually returned to work and picked up the threads of my life… as you can imagine it was a case of looking over “our shoulder” in case the disease returned. I was closely monitored following the treatment, the hospital appointments were as you can imagine extremely stressful. Statistically the likelihood of the AML returning diminished over time with two years being a particularly significant milestone. We eventually reached this point and we had dared to start to believe the nightmare was behind us. Unfortunately this was not to be the case.

ANTHONY NOLAN

BE A MATCH, SAVE A LIFE

I was recently re-tested following what appeared to be a simple bout of flu; I went for routine blood tests which to cut a long story short culminated in receiving the bombshell that the leukemia had returned. I am now back in hospital undergoing chemotherapy however I will as part of the treatment require a bone marrow transplant. I do not have a sibling match so will require a stem cell donor…a search of the database to find a suitable match is currently in progress however I have been advised there are significantly fewer donors on the register from the Asian sub-continent. I wondered why this was, given the vast numbers of “British Asians” (me included) living in the UK. I can only surmise that it is possibly a fear of the donation process which has in the past been shrouded in myth and misinformation; I have since learnt a great deal about the process of becoming a donor and whereas at one time it was an onerous process medical advances have now made it fantastically simple and straightforward. The facts of stem cell transplants are that people from the same ethnic heritage are more likely to have similar tissue types. Currently only 4% off donors on the register are of Asian ethnicity.

To initially register you simply provide a sample of saliva, if at some future date you were asked to become a stem cell donor the process itself is little more than an enhanced blood donation. The impact on the donor is minimal, certainly there are no adverse health implications, your body will simply recuperate… but the outcome for the recipient is nothing short of life saving.

Jenner Large, regional recruitment manager with Anthony Nolan, said, *“Anthony Nolan does everything it can to find matches for the people who need them. However, the challenge increases for a patient from any ethnic background because there are fewer people on the register from these groups. It really is easier than many people think and you could save a life.”* The main criteria to be a donor is the individual has to be between the age of 18 - 40, weigh over 8 stone and generally be in good health. There is an urgent need for young men to join the register as patients outcomes improve when the donor is a young male and sadly, currently only 12% of the entire register is made up of 18 - 30 year old male donors, regardless of ethnicity.

I mentioned earlier that I have a family; I have a wife and two daughters as well as my extended family and friends, I value them greatly and want to be around to help and support them. Take a good look around at your own family and friends and I'm sure you feel likewise. This is an awful disease, it can hit anyone, healthy, old, and young it does not discriminate. It could strike anyone… taking a little time out now to register (honestly it is so simple) will have minimal impact on your life but you can rest in the knowledge that if you become a donor you could save a life. Register now and address the shortfall in Asian donors, we should not need to conduct worldwide searches for donors when there are so many of us here, ultimately we will all benefit. Registering is an “investment” in our collective futures whether it is family friends or the wider Asian community.

More Information

For more information or to register go to

www.anthonynolan.org

Neurological Condition

by, Vaishali Rajesh Shah

My name is VAISHALI RAJESH SHAH and I suffer from an **UNDIAGNOSED NEUROLOGICAL CONDITION** which has had a big effect on me and my life. My condition affects my speech, vision and both fine and gross motor skills as well as my freedom of movement as I am in a wheelchair. Despite the fact that my needs are complex, I manage to enjoy life and achieve my dreams and goals.

Throughout my life, I have been educated in a main stream environment. I started in the Nursery when I was 2 years old and back then I could walk with tripod sticks or a walker. At around 7 years old I started to use a wheelchair because of the growth spurt which made me lose balance due to gravity.

I attended different kinds of treatments which were painful and took a long time.

The people I met in school had a big influence on me and gave me courage to do things as well as able people, by putting in all the effort and hard work into my studies. With the help of computers, (which is one of my lifelines,) and from assistants and my mum, who supported me with scribing and note taking, I managed to do class/home work, assignments, projects and exams in school/college life. Despite all the hardships, last year I completed BTEC Level 3 in Business Studies with Double Distinction.

I have currently started doing a distance learning virtual academy course to achieve English and Maths qualification and I am really enjoying trying out this new type of learning and getting in touch with other people.

Apart from studying I have hobbies that relax me as well as help me interact with friends and family. I like playing card games, board games, socialising, watching movies and going out and about. Also I enjoy listening to music, both Indian and English, and my favourite singers are Lionel Richie and Stevie Wonder. My regular programmes on TV are Neighbours as well as Home and Away. I am a computer fanatic who can spend a whole day playing games on the computer, checking my emails and keeping in touch with my friends on facebook.

My parents have been my supporters throughout my life as they have sacrificed a lot of things to bring me where I am today. Especially my mum, who has never once looked back for herself but has given me all the courage and taught me everything from being a little fragile girl to a smart young lady. Throughout my life she has been my backbone who not only is a mother but also my therapist, tutor, friend, icon and my fashion consultant. My father and mother are my inspiration from whom I have learnt so many values of life, family morals, cultural and religious beliefs and most of all concepts of humanity.

I love and enjoy travelling and my parents have made this possible by taking me on holidays to many different countries where I have been able to explore and enjoy the wonders of the world, cultural and religious sights and sceneries of places from America, Kenya, and India.

I would like to say a huge thank you to both my parents for doing a lot for me in life that has made me what I am today. Apart from my parents, I consider myself very lucky to have been born into a very close and supportive family, both paternal and maternal sides. With so many uncles, aunts, cousins, nieces and nephews, life has never been dull as everyone's love, support and encouragement has enabled me to learn and get somewhere in life. My brother, who is not just a "bro" but so much more to me that I cannot express in words and my grandparents – Dada, Dadi, Nana and Nani, well these are all four to me like my GOD. They have been my parent's foundation stones and with their support, my parents always believed and said to us "never give up and be strong and positive and you will get the taste of the fruits you wish to achieve".

My message to everyone is "Never under estimate anyone from their outer looks but be brave and determined to take all difficult situations as challenges to succeed."

It is with pride and luck that I was born an Oshwal and a Jain. We have done well in every sphere of life and have always supported each other. The same strength and vision needs to be shown when it comes to less able bodies like me and also my parents. They need as much support as I do.

Neuro-diversity

Orlando Bloom, Whoopi Goldberg, Richard Branson, Albert Einstein, Steve Redgrave, Winston Churchill…….The list goes on but what do the above names mean to you? Yes, they are famous and successful in their field. Do they have anything else in common? Answer at the end.

First, I want to share with you some of my journey with two special people in my life.

After years of desperation and heartbreak, I finally became a mum. Bringing our adopted 4 week baby home, made me the proudest person on earth. He came home with all my aspirations for him, his life planned out in my mind. I had an ideal picture of how parenthood was going to be. At last, we were going to be ‘normal’ as perceived by society at that time for a couple, except that it didn’t work like that. In a way, being childless was seen as a disability by society at that time.

Yes, we now had a child but it was by means of adoption so still not ‘normal’! I was asked does he speak ‘gujarati’ when he was a 4 week baby and the classic – do you know who his parents are? Today, I get the question do they know they are adopted? Fortunately, the adoption process and our own strength helped us face society with dignity and rise above the pity.

Back to my gorgeous child, all was going well, most of the developmental milestones were fine - sitting up, feeding, walking, etc. I attended all the usual mother and baby groups and got together with friends with children of the same age. This was great except that it meant I did what we human beings are good at, **COMPARING**. Is your son talking, is he doing this, is he out of nappies…. And the list goes on.

At the back of my mind, there was a niggling feeling but I put this to the side and wanted so much for my child to conform to ‘normality’. He was quite clingy and hated being in public places. He did not crawl and started walking very early or rather running. I was always the mum with the child running around, out of control. We stopped going to people’s houses because of fear of breaking something. As he got older, things got even harder as he would say or do something odd. He would freak if there was something new or we changed the routine. Even today, preparation is paramount before we attend a social function or go to a new environment.

Of course, there was also people’s attitude towards my child. Not many people understood or still understand and can be quite judgmental and hurtful, often without thinking or realising. Even today, I cringe when they ask me something about him when he is standing there and can speak and understand everything. I know it hurts him when people ask about which university he is at or has he got a job? It is not my feelings that I worry about, it is my child’s hurt that I cannot bear. The helplessness at not being able to change things to make it better for him is unbearable at times. He didn’t ask to be ‘different’.

At school, he was always the different one in some way but not obviously. Physically he looks fine but socially he is ‘different’. He loved playing football so was quite happy to socialise with other children who enjoyed the same fervour for running around and kicking balls. The socialising was still a bit different though. Play dates were always hard work. Little fights or little arguments but still no major alarm bells rang. Gradually, things started getting difficult. I made my son's life hell. Why can't you do that, so and so can do it, why did you say that, you have to work harder. In my ignorance or stupidity, I would listen to my friends, do it like this, make him do that….. Then I would question my son, why can you not do that maths or understand what you have just read…. The list goes on and so did the endless appointments with doctors, educational psychologists, therapists, diets, supplements, etc.

I had waited so long for this child, why would there be something wrong with him? Anything I found in newspapers, the internet, word of mouth, I took him to. I spent a fortune. Why? Because I was in denial that my child could be different to what society calls normal. I saw an advert for a learning centre that could help with learning difficulties and as always, picked up the phone, made an appointment, and off we went.

This time, an honest and life changing opinion was given. I was told he had 'mild learning difficulties' and developmental delay. He needed to be in a school that caters for this and not the mainstream academic schools that I had been trying to fit him into. These were added to the labels of dyspraxia, autism, semantic and pragmatic language difficulties, and epilepsy that he already carried. He is not being difficult, lazy or anything else that I had thought of him or been told about him from school, fellow parents and friends. He was doing his best and I had to accept his limitations. However, I was also told that we can teach him to stretch his own ability and nurture his strengths to build on his skills. That was the day that I grieved and breathed a sigh of relief at the same time. So did my son (probably) because I backed off! **MY IGNORANCE MUST HAVE MADE LIFE HELL FOR HIM**. Life became enjoyable again. I accepted him for what he is and let him enjoy his life for himself not for what I wanted for him. The journey since has not been easy and has brought many hurdles with joyous moments too and continues to do so.

Each day, I savour the fact that fate brought this wonderful human being into our lives and has enriched our lives and made us stronger, to the extent that no books, no other person, no material things could ever do. Today, he is a fervent 19 year old facing life in the best way he can, accepting that he is different but also doing his best to 'fit into our society'. I no longer worry about what people may think about his behaviour or his achievements because they are the ignorant ones and we have nothing to be ashamed of. I hold my head up high and savour every thing he achieves because he has worked so hard to do it, it is worth more than any university degree or any other sign of success that society measures with. Each small success that he has, we celebrate as if he has won the Nobel Peace Prize. He may not conform to 'society's norm' but he has special qualities that many don't have. He is the most caring person I know. He has taught me so much about life that no book or educational establishment could have done.

Seven years later, after bringing my son home and after much deliberation of whether we should have another child in the family or not, would it be fair on our son, etc., once again, fate played a part and after a lengthy adoption procedure, we brought my daughter home. This time, I didn't bring home with her, my own plans of her future mapped out in the same way. But I certainly did pray at the back of my mind that this child will be 'normal' or perhaps not have any disabilities because 'I can't cope'. Well, I got my comeuppance for that thought because beautiful and intelligent as she is, she started to show signs of something not being right. Totally different to my son though. Totally with it, at 12 years old, socially and emotionally much more able but academically, here we go…. My first thoughts were oh no, I can't do this again. But somehow, we always get the strength to deal with what life throws at us. She has difficulty with working at speed, her reading and writing skills do not match her verbal ability. Again, teachers used to say, she will never be academic, she lacks confidence, she doesn't try hard enough….. The list goes on. But I am now wiser. She cannot do it because there is a real barrier to her learning. We have found the right school that nurtures and brings out the best in her. What label does this child carry? I have another child that is neuro-diverse but in a different way to my son. She is dyslexic.

So here you have it, **WE ARE THE PROUD PARENTS OF TWO NEURO-DIVERSE CHILDREN!!** My children have taken me on a journey which has resulted in my life, career and out look being completely different to that person who started motherhood with 'an ideal' picture of life. I share my life with others quite openly because we have nothing to be ashamed of. By sharing, I learn so much about helping my children and often, help others who are lost and do not know what they can do. I still have a lot to learn.

Back to the list of famous people.

Were you going to say all those people I named are all neuro-diverse? Yes they are all dyslexic. Does that change your opinion of them? Is dyslexia a disability or an ability?

Neurodiversity (ND) refers to a range of conditions that cause people to process information differently from the way the majority of people do. It includes dyspraxia, AD (H)D, Asperger's syndrome, dyscalculia and dyslexia. These are sometimes called Specific Learning Difficulties or differences.

Dyslexia

Many people still think of dyslexia as being about writing letters back to front, or seeing words move around the page or just being illiterate and even being ‘stupid’. Well, letter reversals and visual distortion are often symptoms of dyslexia due to visual processing weaknesses or disorders but they are not the only ones.

However as more research is carried out, more is known about this learning difference as we realise that there are many areas which are affected by this learning difference, not just reading and writing. Yes learning difference, not a learning disability. People learn in different ways. No two people are the same.

In all, the British Dyslexia Association estimates that approximately 10% of the population will have some degree of dyslexia, of which about 2% will be severely affected. (www.bdadyslexia.org.uk)

Autism

A quote from the National Autistic Society website: ***“People with autism have said that the world, to them, is a mass of people, places and events which they struggle to make sense of, and which can cause them considerable anxiety.”*** (www.autism.org.uk)

Autism affects in particular, the ability to understand and relate to other people. Taking part in everyday life and social interaction can be particularly difficult. Most of us appear to know, intuitively, how to communicate and interact with each other. Individuals with autism have to learn this skill.

Autism is a lifelong developmental disability. It is part of the autism spectrum and is sometimes referred to as an autism spectrum disorder, or an ASD. The word 'spectrum' is used because, while all people with autism share areas of difficulty, their condition will affect them in very different ways. Some are able to live relatively 'everyday' lives with little or no support; others will require a lifetime of specialist support.

Unfortunately, even today, there is still a stigma in society about any learning difference, not just by the person affected but his/her family and friends too. Is it ignorance or fear of being treated differently or unfairly? The reality is that any one who learns differently or at a slower pace is often tarnished with the ‘stupid’ brush, when in fact they can be the gems of any organisation or community, thanks to their often extraordinary gifts.

Everyone has strengths and is good at something. **THINK OF IT AS AN ABILITY AND BE PROUD OF BEING DIFFERENT.**

More Information

British Dyslexia Association

www.bdadyslexia.org.uk

National Autistic Society

www.autism.org.uk

Global Developmental Delay

Our daughter was born at 38 weeks and seemed to be developing normally. Some of her milestones were late for example, she sat at 9 months, started walking (rather clumsily) at 17 months and was only able to say a few words. She had a good pencil grip but could not switch on a light with one finger. She fell all the time. She could not walk up and down stairs the normal way i.e, one foot at a time. She kept dropping things. These are just some examples.

Comments like ‘she’s the middle child, so would talk later’, ‘you are a paranoid mother’, ‘it’s the nappy that makes her walk like that’, from the professional bodies, delayed our reactions to accepting that something was amiss.

Nevertheless, having suspected something was wrong, we pushed the health visitor to assess her at home for a period of 2 hours after which a conclusion was reached that something was indeed wrong. At this stage, we as parents were still in denial about her issues, partly because we didn’t really appreciate the extent of her difficulties, the need for a ‘typical’ child and the lack of any conclusive evidence by the health professionals.

Soon after we went on holiday to Canada where a family GP suggested we should get an opinion from a developmental paediatrician. Following an assessment, he diagnosed her as ‘hypotonic’ (low muscle tone), with speech and language delay.

This hit home hard! To some extent we started going through a grieving process of denial, anger, mourning but not yet acceptance.

Back home, we approached the NHS for help and direction. We saw a community paediatrician, occupational therapist (OT) and speech therapist (ST). The help and processes frustrated us greatly with irregular provisions, lack of a MDT approach and no real answers. In order to get things moving quickly, we decided to give our daughter regular private OT and ST. Our daughter was now 2 yrs old and we started noticing behavioural problems. These stemmed from her lack of communication skills and our inability to understand her further exasperated by her lack of fine and gross motor skills.

Her progress was very slow and highly frustrating. As parents, we were still of the belief that things would change and she would be a typical child. Our lack of understanding led to the development of anxieties and confusion in her. To look at, no one would be any wiser of our daughter's condition as she looked normal. Perhaps that was what we wanted to see as well. However having a third child and observing his normal developmental progress brought home to us the realisation of the widening gap in our daughter's development, compared to the norm.

Between the ages of 3-5 and a half, she changed 3 schools due to the fact they didn't have the resources or knowledge to deal with her. Finally through a private educational psychologist assessment, we were referred to a small independent school that specialised in children like our daughter. We visited the school and once she was accepted, this was the point at which we finally accepted that this was to be a long-term condition with challenges that may be life long.

Our daughter settled down very well and gained in self-confidence and self-esteem. Her progress is still slow but she is improving continuously and our goal is to make her independent, self sufficient and happy.

We found the educational and health system not to be very helpful and became disillusioned by it. It seems for conditions such as hers, it is a mine field even for the professionals so what hope is there for the layperson?

Our daughter has never been given a diagnosis and so came under the umbrella of Global Developmental Delay. Through various assessments and reports, we are just beginning to understand her condition. To summarise these, our daughter has a sensory-based motor disorder with a postural disorder and speech and language delay. She is a very happy child who gains information of the world around via her senses particularly vision, smell and touch.

Children like her can learn but need the opportunity to learn from non-traditional ways such as visual, kinaesthetic and through repetition, praise and encouragement. It needs understanding and patience on our part and an ability to see the world through her eyes.

In spite of all the challenges we face and will continue to face, we feel blessed to have a beautiful and loving daughter who has taught us humility and acceptance that every child is special and have their own unique needs. Her progress may be slow and her accomplishments small and she may require support for years to come but she was given to us as a special child who plays a leading role in our lives.

An Overview of Global Developmental Delay

A Global Developmental Delay is a general term used to describe a condition that occurs during the developmental period of a child's life (birth to age 18). It is usually characterized by lower intellectual functioning and is accompanied by significant limitations in communication, self-care, home living, vocational, academic skills, leisure, health and safety).

Global Developmental Delay has many different causes which ultimately affect the functioning of the central nervous system (Trauma to the central nervous system, Fetal Alcohol Syndrome, genetic disorders, metabolic disorders, etc).

Common signs may include:

- delayed acquisition of milestones: the child is late in sitting up, crawling, walking
- limited reasoning or conceptual abilities
- fine/gross motor difficulties
- poor social skills/judgment
- aggressive behaviour as a coping skill
- communication problems

More information

Mencap

www.mencap.org.uk

Peaks and troughs of a Family Facing a Disability Issue

By, Urvina and Vijal Shah

Disability in whatever varied form it arises is like a hurricane that swirls around furiously and has an impact reaching far beyond its central core called "the eye". However, unlike the natural version where the spiralling wind and storms eventually fizzle out, the storms created by a disability in most cases is for a lifetime and its trail of emotions is a tangled web that knows no end.

The spectrum of emotions is such that a mere article such as this only provides a cursory glance into an environment that at one end is full of distress and woe and at the other also immensely enriching.

In our case, faced with a young child with a learning disability i.e. a virtual disability buried deep into the child's psyche, the rollercoaster of emotions - the peaks and troughs - are challenging to say the least.

Troughs

The emotional terrain encountered ranges from confusion, denial, sense of loss, hopelessness, anger and most worrying of all is the uncertain future that the child will face as she gets older in a world that is increasingly intolerant. For the parents, siblings and the extended family their state of mind is always on a cliff-edge.

The impact of the disability on the entire family is a unique family experience and affects all aspects of family functioning. For example:

Changes in home routines – this has to be specifically set out from the outset and weighted more towards the affected child than others – scope for spontaneity is limited.

Relationships between siblings – this can be strained due to lack of understanding, particularly when siblings are at an age where tolerance levels have not matured.

Vocational life – Professional goals/aspirations and basic life assumptions when starting up a family need to be evaluated to align the demands of the affected child.

Relationship impact between the parents – the strength of this is of paramount importance and the key to this is maintaining emotional and verbal communication at all times and diffusing any other noise from this.

Relationship impact with extended family – this can be challenging as members of the extended family, whilst supportive and providing a haven for emotional respite for the parents or the siblings are nevertheless bystanders to the drama occurring on the front line.

Financial costs – family financial resources will inevitably be strained as these will be diverted to treatments, consultations and schooling if applicable for the affected child and at the same time balancing the financial needs for the rest of the family.

Peaks

Without demeaning or denying the challenges presented to families with a disabled person, there are many positive aspects that we as a family unit have gained such as:

- Not to take things for granted
- Tolerance and sensitivity
- Learning to be patient
- Putting oneself in the world view of the affected child building a greater knowledge about disability issues.
- Expanding a wider social network to encourage a

broader assimilation of ideas.

- Adopting a broader outlook for self and the other siblings
- Increasing our inner strength
- Enhanced family cohesion
- Encouraging connections to community groups.

It is important to emphasize that these strengths are available to most families who are simply “raising a child”. However, these positive adaptations are more pronounced to ensure a better coping strategy is developed when faced with a difficulty.

Counselling

An essential part of the coping strategy is to seek counselling. The ability to wade through the emotional troughs mentioned above through the power of counselling cannot be underestimated. As a couple, counselling helped us to articulate our thoughts and made us realise the extent to whether we were truly aligned in our approach to help our child.

Whilst family support is paramount and provides the virtue of fortitude to persevere and overcome the tribulations in one’s life, seeking outside help is an essential part of getting some clarity of thought. An independent counsellor whom we met over a period of months was a great source of help. We felt however that an even more powerful source of strength was linking up with other affected families. Sharing experiences and war stories with people who are in a similar position, is a powerful way of putting things in perspective. One immediate negative it erases from the mind is the feeling of isolation.

Community Network

Seeking out an appropriate counsellor or even affected families was not an easy process and certainly something you could not easily tap into or out of easily. There are resources and a multitude of organisations from outside our community but we feel that the community network is a good starting point for families facing disabilities as they share the same values, beliefs and culture.

As part of last years’ successful Oshwal Career & Development Fair, a small group of individuals were asked to organise a small workshop focused on disabilities issues faced by members of our community. From this, Enabling Network (EN) was formed led by Urvina. EN has empowered us as it has given us an opportunity to share our experiences and meet interesting and like minded people.

We hope that Enabling Network provides an effective forum that can not only support families affected by disability but also raise awareness to help instil understanding and banish myths regarding all disabilities in the wider community.

This in itself will go a long way to help affected families move away from the troughs and sustain the peaks.

More Information about Enabling Network

Tel: 07981 130 471

Email: en@oshwal.org

Web: www.oshwal.org

raising
awareness
about
disability

ENABLING NETWORK
Embracing all Abilities

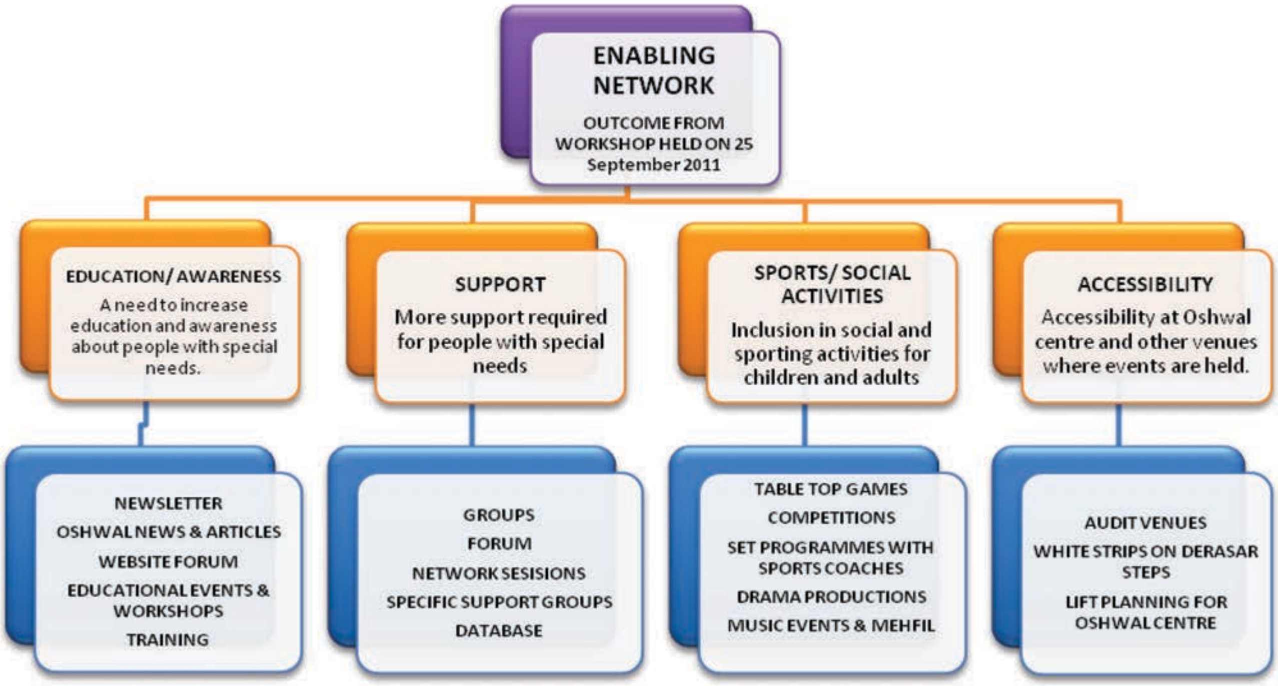
Part of the Oshwal Family

OSHWAL
Association of the UK

ENABLING NETWORK (or “EN”) has been formed with the guiding principle of “Embracing all Abilities”. The key aims of EN are to change perspectives, raise awareness and instil an understanding about disabilities (such as physical disability, learning difficulties, visual difficulties, etc) to create a community of openness, tolerance and social inclusion at all levels (such as religious functions, social events, sports activities, etc).

Workshop on Disability Issues

To this end the EN team organised a workshop back in September 2011 to both highlight disability issues within our community as well as engage people with special needs to see what we as a community can do better. Since the workshop, the EN team has been busy analysing the data collected and devised some plans to take this feedback forward. The flow chart below summarises this analysis.



Since the Workshop on Disability Issues the EN team has been engaged in a number of activities, highlighted below, to raise awareness of disability issues within our Oshwal community.

Oshwal Health Awareness Day

Overview

The EN team took part during the recent Oshwal Health Awareness Day on 13 November 2011 at Oshwal Centre, to raise awareness about disabilities issues. The focus was on guiding Oshwals affected by disability to external sources of help as well as raising awareness about what the requirements of disabled persons are, such as to have occluded spectacles to demonstrate the difficulties faced by the visually impaired.

Volunteers Help

Aside from the EN Committee Members, many volunteers helped out at the EN stall at OHAD. These volunteers came directly from the attendees of the EN Workshop, which was held earlier in the year on 25 September 2011 at Oshwal Centre. The volunteers included: Bakul Shah, Deep Shah, Hiten Shah, Jyoti Shah, Parul Shah, Roshni Shah, Sanjay Shah, Suresh Shah, Varsha Shah, Vijal Shah.

It was great to see so many volunteers come on board and help the EN team out. Many of the volunteers were directly affected by disabilities themselves and provided valuable insights into raising awareness of disability issues.

Making Contacts

The OHAD was a great forum for making new contacts within the wider Oshwal and Asian community with organisations which cater for the needs of the disabled. EN team members took the opportunity to network with several of these organisations and will be looking to see how these can be developed to see how benefits to Oshwal members can be realised.

Oshwal News E-Magazine

Published in December 2011 on the Oshwal Website

EN worked with Oshwal M&C team to produce an e-magazine to celebrate the International Day of Disabled Person 2011.

The annual observance of the International Day of Disabled Persons was proclaimed in 1992, by the United Nations General Assembly. The observance of the Day aims to promote an understanding of disability issues and mobilize support for the dignity, rights and well-being of persons with disabilities. It also seeks to increase awareness of gains to be derived from the integration of persons with disabilities in every aspect of political, social, economic and cultural life.

This E-Magazine is available for download from the Oshwal website (www.oshwal.org). The EN team are pleased to report that various articles have been contributed towards this E-Magazine and hopes it will greatly help to raise awareness about disability issues.

For more information, contact the Enabling Network team on:

E-mail: en@oshwal.org | Mobile No: 07981 130 471 | Website: www.oshwal.org

Oshwal Lift Project

Improving Accessibility at Oshwal Centre

One of the primary needs for many people both disabled and elderly, is better accessibility at Oshwal Centre between the upstairs and downstairs halls. EN team have been researching various options for the installation of a disabled lift facility at Oshwal Centre.

EN members have drafted a report for the Oshwal Lift Project and have submitted a copy to the Property Management Committee for their consideration.

EN team would encourage and urge the EC members to put in place a formal plan for the installation of a lift at Oshwal Centre to improve accessibility.

Forthcoming EN Events

The following activities are planned by EN for 2012. Watch out for more details soon on E-newsletters and Oshwal Website.

Spring time: Be Informed Talk and Social Event

Short presentations by speakers on learning differences, Autism, Cerebral palsy and visual/hearing impairment.

Informal social to share information and ideas.

Summer time: Disability and Inclusive Education weekend

A mega 2-day event will be a combination of talks, workshops for advice and benefits, practical sessions for various disabilities and educational needs such as educational statements. A play/movie may be planned for this event too, all with a view of raising awareness about disability issues and to encourage more integration of able and disabled members of our community.

Dates, venues and times for the above events to be confirmed and may be subject to some changes.

The following are also being worked on by the EN team:

Sports Inclusion – integration of sporting activities for able and disabled members.

Making it happen!

EN has been recognised as an official sub-committee of the EC and all 14 members of the sub-committee are either directly or indirectly affected by disability and we will do our utmost to fulfil the role expected of us by the community for the community.

Our hope is, that this in turn, will empower and inspire both the able and less able to be part of a community that is rich in talent, knowledge and skill and are willing to share this with each other.

For more information, contact the Enabling Network team on:

E-mail: en@oshwal.org | Mobile No: 07981 130 471 | Website: www.oshwal.org

As an Oshwal Member always first consider hiring facilities at Oshwal Centre (Potters Bars) or Oshwal Mahajanwadi (Croydon) for your functions. By hiring these Oshwal venues you will be supporting your community.

Weddings - Parties - Functions - Dances - Meetings - Conferences - etc.

Phone the Administrators at either booking offices regarding hall availability and charges.

OSHWAL CENTRE
Coopers Lane Road, Northaw
Hertfordshire, EN6 4DG

Tel: 01707 643 838
Fax: 01707 644 562
Info Line: 01707 661 066 (Recorded Messages)
Email: admin@oshwal.org
Website: www.oshwal.org
Office is open 7 days a week from 9am to 5pm

OSHWAL MAHAJANWADI (Croydon)
Oshwal house, 1 Campbell Road
Croydon, Surrey, CR0 2SQ

Tel: 020 8683 0258
(2pm to 5pm weekdays only)

Gujarati School Office
Tel: 020 8664 9807
(9.30am to 12.15pm Saturdays only)

Marriage Registration

Both Oshwal Centre and Oshwal Manajanwadi are registered buildings for the solemnisation of marriage. Registration of a marriage at both venues will be part of a religious ceremony, i.e. it will take place during and within the Jain / Hindu religious marriage ceremony. For further information, please phone the administrators.

Sadadi

If you would like to find out whether a Sadadi is being held at Oshwal Centre or Oshwal Mahajanwadi, in respect of any deceased Oshwal, you may ring the Information Line at the Oshwal Centre and a Recorded Message will advise of the time of the Sadadi and the name of the person in whose memory the Sadadi is being held.
Information Line Tel: 01707 661 066 (Recorded Message)

Obituary / Shraddhanjali Messages

The rate for inserting an Obituary / Shraddhanjali message in Oshwal News is £150.00 per page per issue. Please ensure that wherever possible a passport sized photograph (preferably in black and white) is enclosed with the message which also should be **written out very clearly and neatly**. Please enclose your cheque and SAE for the return of any photos. Please note that it will not be possible to entertain any requests for proofs of these messages prior to printing.

Learning & Development Exhibition

Bringing together local experts from Education, Special Needs, Medical Professions and Performing Arts

Date: Sun 29 January 2012, 11.30 am - 2.00 pm
Nower Hill High School,
George V Avenue, Pinner, Middlesex HA5 5RP
Admission: Free

Special Needs

Learning Resources

Alternative Therapies

Nutrition

Dance for Special Needs

Medical Professionals

Counselling

Confidence Building

Multi-Sensory Tuition

This event is promoted by:

Help 4 Learning

www.help4learning.com

Tell us what you think of the E-magazine??


OSHWAL news
e-magazine
First Ever E-Magazine | December 2011 | www.oshwal.org
Special Edition
Celebrating the 2011 International Day of the Disabled Person
in association with
ENABLING NETWORK
Embracing all Abilities

Did you like this first E-magazine?

Would like to receive E-magazines on a regular basis?

What other themes can we explore in E-magazines? E.g. Finance, Health & Wellbeing, Education.

COMING SOON
Watch out for flip PDF E-magazines!!

Email you comments & feedback to:

oshwalnews@oshwal.org