



Kingston Centre For
Independent Living

"Not Seen - Not Heard"

Black & Minority Ethnic* Disabled People

A Black History Month Resource

October 2007

*The term Black and Minority Ethnic (BME) is used in this document to include people of African, Asian, Caribbean, Chinese, Irish, Jewish, Korean, Mixed Heritage, Refugee or other ethnic minority backgrounds.

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Foreword

Welcome to KCIL's second Black History Month Disability Resource.

Last year's Resource, "Holding up a Mirror", sought to address the relative invisibility of disabled people in general, and of BME disabled people in particular, by identifying images of disabled individuals from Black and Minority Ethnic backgrounds, many of whom have contributed significantly to Black, disability and mainstream society, and highlighting their achievements. This relative 'invisibility' is accompanied, perhaps understandably, by a corresponding 'silence' so that rarely, if ever, do we hear or read first hand accounts of the lives, hopes, fears or aspirations of BME disabled people.

The old Victorian saying, "Children should be seen and not heard." seems also for many years to have applied to disabled people although, in their case, the rather harsher instruction seemed to be, "Disabled people should not be seen and not heard.". With the advent of disability movement pioneers, this view has gradually been challenged. However, for many reasons, BME disabled people are today often still not seen and not heard.

Consequently, we have sought to amplify BME disabled people's voices in this compilation of either first hand accounts by BME disabled people and/or their family members about aspects of their lives, or through articles or reports written about them and their lives.

We are grateful that contributors have shared their experiences of being BME disabled people in this Resource. We hope that it will add to the BME disability debate and look forward to a time when all disabled people are very much seen and are very much heard.

Finally, we should like to thank City Bridge Trust, who fund our BME disability project.

Veronica Attah
BME Disability Officer
KCIL (Kingston Centre for Independent Living)
October 2007

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What are the Social and Medical Models of Disability?

The **medical model of disability** defines disability as the disadvantage or restriction caused by a society, which takes little or no account of people who have impairments and excludes them from mainstream activity.

For instance, lupus, sickle cell, heart disease and arthritis are usually considered unwanted medical problems. The solutions tend to be based around the idea of curing the person or at least making the condition better. This is the classic medical model of disability, which can make people feel they are inferior to everyone else and a burden on family and friends.

The Medical Model Says:



- You are the problem
- Your disability needs curing
- You can't make decisions about your life
- You need professionals to look after you
- You can never be as equal as a non-disabled person.

The **social model of disability** tries to give a more positive image of disability, by saying that disabled people shouldn't be seen as a medical problem. This is not to say that medical help is wrong or unnecessary. However, the medical model describes a situation where "people with impairments or illnesses cannot be seen as equal with everyone else unless they get better". (*Young Arthritis Care*)

To criticise this doesn't mean that health improvements are not considered desirable; just that our chances of success in life should not depend on them. The social model says that we should organise society so that we are all equal whether we have a long-term condition or not. This means gearing services to accommodate people as they are, rather than trying to

change those people.

However, many people from Black and Minority Ethnic Communities are used to receiving obtuse medical advice and guidance and do not know anything, or very little of the Disability Movement and “new words” such as the Social Model and Independent Living. Many are more likely to relate to the medical model of not being able to get up the stairs because they are in pain! And not that the stairs could/should have a stair lift!

Equalities (ENC, Equalities National Council of Disabled People & Carers from Black & Minority Ethnic communities) believes that a lot more work needs to go into developing a model which is a mixture of both the medical and social model, in order for disabled people and those with Long Term Impairments to relate to it.

The Social Model Says:



- “Disability” is not an individual problem
- We can’t compete on equal terms because there are too many barriers
- We need to recognise that “society” (through government and its agencies) has a duty to remove these barriers
- Disabled people have the same RIGHT to full equality as do all other citizens.

Source: “Nothing For Us Without Us”, July 2007, Equalities National Council of Disabled People and Carers from Black & Minority Ethnic Communities (ENC).

See also: [The Social Model of Disability in words and pictures \(PDF\)](#) 
[The Medical Model of Disability in words and pictures \(PDF\)](#)

Images are from The CHANGE Picture Bank: www.changepeople.co.uk

I am... God Damn

by Semba Jallow-Rutherford, Performance Poet

I am a black disabled man

That's who I say I am

I am an African

An African disabled man

That is who I am

God damn

Meet me eye to eye

Then try to take me on

Mr. politician

Mr. policeman

Mr. preacher man

I say take me on

God damn

For I am who I say I am

An African disabled man

Come and take me on

Racist institutions

Come and take me on

You ignorant ones

God damn

I am who I say I am

When you look at me

You'll see a black disabled man

Not just a black man

Nor a disabled one

I am an African

An African disabled man

I say come and take me on

All you medicine men

All you informed ones

God damn

Come and take me on

I am not a sick man

I am not a case note

I am not a freak show

God damn

I am who I say I am

I am who I am

A black man

An African

An African disabled man

Look at me and

Tell me what or who you see

You see a man

An African

An African disabled man

For I am who I am

God damn

I am not the wheelchair that I sit in

Not the walking cane that I walk with

Nor the dishevelled frame you're looking at

I am a black man

An African

An African disabled man

God damn

I am who I am

I am who I say I am

God damn

God damn

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Claudia Mark

Claudia Mark, 40, is being funded by Scope's Give It A Go awards to carry out a photography project called Where Am I? This will lead to an exhibition as part of Black History Month in October.

She took photographs of over 50 people from ethnic groups with disabilities and also asked them questions about their life, attitudes and experience.

Claudia, who has systemic lupus, says: "One of the issues I had is that there are very few images of black disabled people.

"I am a black disabled person and felt there was nobody to relate to. I had no role models.

"I felt I was missing. If I am missing, are there other people like me who feel they don't belong to the white disability movement or to the black community?"

Extract from an article first published in Disability Now, July 2002:

http://www.disabilitynow.org.uk/search/z02_07_Jy/millennium.shtml



Graphic by Paul Lareau - <http://www.lareau.org/disgraph.html>

Kelle's story

Singer Kelle Bryan was topping the charts with [girl band] Eternal when she was suddenly struck down [with lupus].

"I could feel the adrenalin pumping through my body as I sang to a crowd of 100,000 people at London's Party in the Park. On that sunny day in Hyde Park in July 1998, it felt like Eternal had made it - we'd topped the charts in the UK and in America and had sold millions of albums. But, below the surface, I was having real problems with the other band members. We were always arguing and it felt like they were freezing me out.

A week after the Party in the Park, I received a fax from the other 2 girls saying they wanted me out, I knew things were bad but, after 6 years together, I didn't expect this. Over the next 3 months, I consulted lawyers and we finally agreed on an out-of-court settlement. The whole thing was incredibly stressful but I knew I had to move on, so I decided on a solo career.

Days before I was due to start recording my first album in Italy, I came down with a bad cold. I felt groggy but wanted to keep going. After a week, my manager sent me home as I just couldn't shake it off. Infact, I'd got worse - my whole body ached.

My doctor diagnosed post-viral syndrome and told me to take paracetamol for the aches. I rested for a few weeks, but still felt dreadful. By now my mouth was covered in ulcers, I had a scaly rash across my cheeks and my legs were really swollen. My mother and my boyfriend of 5 years, Rene, were really concerned, so I went to see a specialist. He gave me steroid injections but couldn't give me any diagnosis beyond what my doctor had said.

The injections worked at first, but then the stiffness and aching spread through my body to the point where I couldn't walk. Rene had to carry me to the toilet. I was frightened and confused, as I had no idea what was wrong with me.

We decided to get a second opinion. Dr David D'Cruz, a rheumatologist in London (now at the Louise Coote Lupus Unit), said I may be suffering from something called lupus, an autoimmune disease and admitted me to the hospital for tests. I felt relieved I was finally going to find out what was wrong with me. After a week of biopsies, blood tests and even neurological tests using electric shocks, I was diagnosed with SLE, the most common type of lupus, caused by the immune system attacking the body.

The doctors explained there was no cure, but that steroids and medication would help. They told me lack of mobility, the rash and stress on major organs were common and because it had taken so long to diagnose there was already some damage to my kidneys and liver. They said I might never get back to full strength and I could be in a wheelchair for the rest of my life.

It was impossible to take in. The doctors left the room and I just thought 'this is it. This is my life'. But then I started thinking about remissions - the doctor said I might get better for short periods - and I started to feel stronger and more hopeful.

From that moment, I refused to accept the picture the doctors had painted for me - I was not going to be a patient for the rest of my life. When I next saw mum and Rene I was defiant. 'I'm going to do everything I can to get better' I told them.

I stayed in hospital for 10 more days, until the steroids took effect. The doctors had said stress was a possible trigger for the lupus. Not really surprising considering the legal battle, plus I'd been working non-stop with Eternal since I was 15.

After leaving hospital, I spent a few weeks at a recovery unit in Hertfordshire before going home to London. I was able to move again because of the steroids but, after 3 months in bed was very weak. I decided to set myself small goals; little things like walking to the bathroom unaided. To strengthen my arms, I lifted cans of beans, but I'd only manage a few. Some days I was so exhausted I was in tears but I was determined not to give up.

2 months later, I started recording again. I'd literally sing 1 line then rest for half an hour. By the end of the year I was ready to promote my album. Dr D'Cruz advised me to wait until I was more stable, but it was what I lived for. So, in early 2000, I flew to LA for the video. But the night before filming I was brushing my hair when great chunks started to coming out. It was the final straw. I just collapsed on the floor crying. My doctor said it was a side effect of the steroids, so next morning I was sent to an alopecia clinic for a wig.

We went ahead with the video, but I was still weak and had to sleep four or five times a day. During interviews to promote 'Higher Than Heaven' I'd get convulsive shakes that meant I'd have to stop, take some medication and sleep for an hour before I could go on. But it was worth it - despite being exhausted, I felt I'd proved to myself I could still succeed.

Back in the UK, I resumed my rehab programme, In time my hair grew back, my skin healed and by 2002, I had halved my steroid intake and started jogging. I even took up kickboxing and in 2003, to everyone's surprise, entered a tournament and actually won! I also decided to start

my own record label, Red Hot.

By the end of 2003, I came off my drugs completely. I hadn't had any flare ups and in 2004, I had a full medical that showed there was no trace of any lupus activity in my blood. Although doctors warned me it could come back, I feel healed.

Today the only remnants are scars and the odd twinge in my kidneys. So few people know about lupus, but it particularly affects young women. I became a Patron of the St Thomas' Lupus Trust to help raise awareness. My advice to anyone is to think positive - I was determined not to let lupus ruin my life and I believe that's how I found the strength to get better."

"This article was first published on the St Thomas' Lupus Trust website. It is Copyright St Thomas' Lupus Trust website. All rights reserved. <http://www.lupus.org.uk/index.php?i=20>

October is Lupus Awareness Month.



What is Lupus?

Lupus is the Latin word for wolf and lupus vulgaris, a severe facial rash which is rarely seen now, was once thought to resemble a wolf's bite.

It is a chronic (long-lasting) incurable autoimmune system illness, probably genetic in origin and mainly suffered by females, where the immune system, for unknown reasons, becomes hyperactive and attacks normal tissue. This attack results in inflammation and brings about symptoms. It is more common in black and Asian women than in white women.

Some 50,000 are now thought to have lupus in the UK - it's systemic, in that it can affect any part of the body.

Worldwide it's acknowledged as being more common than leukemia, muscular dystrophy and multiple sclerosis, and those conditions (and others) share a number of similar symptoms.

Lupus can produce many symptoms and family doctors often fail to recognise it. Meanwhile, a number of major organs can be damaged in an irreversible way.

The two major symptoms are joint and muscle pain and an extreme tiredness that won't go away no matter how much you rest.

Rashes, depression, anaemia, feverishness, headaches, possible hair loss and mouth ulcers may all be part of the pattern of lupus.

Noticeably, whilst the two major symptoms are invariably present, people with lupus can differ greatly in their symptoms and how the illness can affect them - life-threatening for a few, very mild for some.

Source: <http://www.lupusuk.com/qanda.asp>

Growing up Asian American with a Disability

by Grace Tsao

Disability is still a taboo topic within many parts of Asian cultures. People with disabilities are often seen as outcasts of society and worthless citizens. In many modern-day Asian countries, the disabled are still regarded as incapable of becoming educated, functioning members of society. Therefore, they are often forgotten and fall beneath the cracks. This old school of superstitious thought teaches that disability is some sort of punishment, and promotes the idea that being different is always a horrible thing.

Growing up as an Asian American female with a disability, I was always fully aware of how my culture played such a significant role in my life. This was especially evident in the way my parents tried to shelter me. I can remember distinct times when I was younger when my parents did not allow me to attend certain functions where a lot of first-generation Chinese, other than family, were in attendance. However, my younger brother could attend. I could not understand the reasoning behind this - after all, I was the eldest. I began questioning my parents. Their response was that they were protecting me from the Chinese elders who would not understand or accept my disability. They told me that these traditional Chinese would gawk at me and gossip about the fact that I use a wheelchair. They would look down on our family because only a family who has done wrong would deserve such a fate and shame. I didn't believe my parents at first. In fact, I accused them of being ashamed of who I am. They kept assuring me that they loved me no matter what, and that this sheltering was for my own good, because not all people would view disability the way we did. I believed them.

My mother would often tell me that the perceptions these people held about disabilities came from superstitions in Asian culture that bad things could only happen to people who have done wrong. That if you live a decent life and are essentially “good” you are virtually untouchable. Where the distinction or judgment about what is “good” or “decent” comes from is debatable. In my culture, however, being diagnosed with muscular dystrophy at age seven meant being seen by some as a form of chastisement or bad karma inflicted on my family for moral wrongs my family may have done in the past or present. In fact, any disability, whether from birth or as a result from an accident, would fall under this category of “punishment.”

Even my grandmother possesses these thoughts. She will often make comments about people who seem to encounter many hardships by dignifying their fate, saying they probably deserved what happened to them. For example, she made a similar comment about a family who had a relative stricken with cancer. These comments are rather harsh, but superstitions are often embedded in a particular culture. And like all superstitions, they can be proven wrong, as people are willing to look at individual experiences and become more open-minded.

This stigma of being a triple minority has followed me throughout life. I have always been fully aware of my existence of as female, disabled and Asian American. I began having negative perceptions about Asians. I had no concept of what Asian American was. All my friends were white; I avoided Asians at all costs. After all, they had negative ideas about me, so why should I try to get to know them? It was not until halfway through high school, when I began to join extracurricular organizations, that I changed my outlook. I met many open-minded Asian Americans who did not treat me as an outcast, and who accepted me. I had a sudden realization: I was

prejudiced and hypocritical. I had been judging people based solely on outside appearances and stereotypes. These were the very things I hoped others would not judge me by.

Often, Asian Americans do not grow up with the same mindset as traditional Asians. They are influenced by the whole concept of East meets West, but do not necessarily adopt the traditional closed-minded values. I'm not saying that all immigrant or first-generation Asians are closed-minded Neanderthals, that would be closed-minded of me. No generalizations can be made about any group of people. I also realize that, as people from across the globe are being educated about disabilities, these traditional ideas are slowly being replaced by more accurate perceptions. My thoughts and views are shaped by my own personal experiences.

There are many aspects of the way my parents have raised me that would have differed dramatically if I would have been able-bodied. In many ways the situation of me being disabled overshadowed many traditional Asian values they may have held. They did not exert the academic pressures that are common to Asian households, on me. Most Asian families that I knew put constant pressure on their children to be more successful than everyone else academically. Being second best was not enough. Now, some would argue that is not necessarily a bad thing. But telling your child that failure is not an option at any cost can be damaging to a child. I have known Asian kids who feel that they must constantly "be the best," in order to prevent disappointment in their parents. They have gone as far as making important life decisions such as what they plan to devote their life's work to in order to satisfy their parents. In many cases, kids chase their parents' dreams, not their own. The constant tensions and not pursuing their own dreams may lead to burnout and eventually failure. I know my parents

would have pressured me a lot more to succeed academically if I did not have a disability. But, they did care about education and wanted me to succeed at my own pace. Failure was all right if I tried my best. They always expected that I would attend college and receive my degree, despite my disability. They encouraged me to pursue writing, which is often not as lucrative or stable as those fields dealing with science and technology. I feel that my parents' more lackadaisical attitude than most Asian parents helped me to succeed. I am doing what I want to do in life and on my own accord. I received my Bachelor's degree in Journalism and am pursuing my Master's degree with a focus on Multicultural Education. Culture and writing has always been incredible influences in my life.

The subjects of romance and marriage were not an issue because like many people, my parents never thought that people with disabilities were capable of being involved in romantic relationships. So this topic has never really been brought to discussion. However, lately my parents have come to a realization that this is possible. I really feel that they would be very accepting if I were to marry someone Caucasian, because they feel that an Asian man would never be able to look past my disability. If he could, his family probably would not. This is speculation on my part because I really do not know how my parents feel. I can only make inferences. I can see this in the way my mother reacts to my Asian friends. She is almost surprised that someone who is Asian American can look beyond my disability and accept me as their friend. This is due to her own innate prejudices about how people of Asian decent view the disabled. Staying within my own culture concerning issues of relationships and marriage would have also meant more to them. I can see all of this from the extremely different reactions they have on these issues when other relatives or other Asian families are involved. In many ways my parents

have become much more open-minded in the way they raised me because of my disability.

Having a relationship at this point in my life is a very touchy subject to deal with. As someone with a disability, it is difficult to find someone special that will look past my disability. In this society where physical perfection in women is so important, I have yet to find someone that will look past my outer shell and into the person inside. Much of this comes from the fact that I am in a very transitional period in my life. I am slowly crossing the gap between late adolescence and into full adulthood. At barely 22, I feel that guys my age have just begun to care less about what others think and are beginning to decide what is best for them. As young people, we are very influenced by what our peers think. Because of my experiences as a triple minority, I know what it is like to be judged by stereotypes and outside appearances so I strive hard not to judge others by the same.

Being a triple minority is a difficult role to play in life. You don't fit in within mainstream society or your minority in-group. You must also struggle as a female, in a male dominant society. You are not sure where you fit in. I believe that you need to keep an open mind and try to educate others. If you don't, you'll go through life on the outside looking in.

Text © 2000 by Grace Tsao

Source: [http://www.colorado.edu/journals/standards/V7N1/
FIRSTPERSON/tsao.html](http://www.colorado.edu/journals/standards/V7N1/FIRSTPERSON/tsao.html)

What is Muscular Dystrophy?

There are about 60 different types of muscular dystrophy and related neuromuscular conditions. These conditions are characterised by the loss of muscle strength, as progressive muscle wasting or nerve deterioration occurs. They are mainly inherited, can cause shortened life expectancy and there are currently no cures.

Neuromuscular conditions affect boys, girls, men and women of all ages, occur across all ethnic groups and often more than once in one family. We estimate that there are about 30,000 people in the UK with a neuromuscular condition. When family members and friends are included, over 150,000 are affected by muscle wasting conditions.

The cause of [many] of the conditions ... is genetic. That is why so much research has already gone into finding which genes are at fault and how they might be repaired. The genetic risks vary.

In some types of neuromuscular condition both the father and mother must have a faulty gene to pass it on. This is called recessive inheritance. In other types, it only needs one parent to pass on a faulty gene. This is called dominant inheritance. In Duchenne muscular dystrophy the mother usually passes the faulty gene on to her son. This is called x-linked inheritance. Progress in research means that once one member of a family is diagnosed it may be possible to test other relatives to detect carriers.

Not all conditions are inherited however. Some conditions are known as being "autoimmune". That means the immune system turns inwards to attack targets within the body rather than fighting off external dangers. And there can be a new mutation (or change) in the genes that causes types of neuromuscular conditions to appear for no apparent reason.

There is, as yet, no cure, but there are ways of treating the symptoms of some conditions (like myotonia congenita) and there is much that can be done practically to improve life for those affected.

Source: http://www.muscular-dystrophy.org/about_your_condition/introduction_to.html

Two extracts from Interview 10 Transcript: “A 41 year old Irish gay male living in London for 20 years, who was diagnosed in 1998.”

You know, I've sort of been the minority and I'm in London as an Irish man. In Ireland as being a gay protestant. In the Republic, you know, sort of a minority. And then you sort of come here and you become HIV positive. So it's all minorities all the way. So it makes you, it makes me very intolerant to people who don't... who are racist or prejudiced in any way. I have absolutely no time for it. And in sort of situations like that I find that I can't ignore it either. I have to stand up and say, 'This is not right. This is not, you know, you cannot think these views', I mean, 'You can think them but they're not correct.' And I have to express myself and tell them. I can't sort of let somebody say something and sort of think, 'Well, OK, I'm not going to challenge that or whatever.' I have to get in and sort of say, 'Wrong.'



I guess HIV's made me more aware of time. Every minute of the day is mine and how I choose to spend it is mine. It makes you a little selfish. I don't waste my time or if I do waste my time it's because I have chosen to waste my time. But it's like if I make an appointment with somebody to do something at sort of ten o'clock and they don't turn up until eleven, then I'm really annoyed because they've wasted an hour of my time. And I consider my time precious because it's limited you know. So, like if I chose to waste an hour, that's my decision, I've consciously decided that I'm going to do nothing for the day or whatever but... I sort of pretty much only do what I want to do really. You know, if I spend time with you it's because I want to spend time with you. It's not because I feel I have to or whatever, because again, it's my time and it's limited.

Two extracts from Interview 30 Transcript: “A 45 year old highly educated health professional working full time. He is a black African man married with children.”

I'll tell you one thing. When I was told it was a week before Christmas. Yeah I was actually told on 14th December 2000. That's when I got the results. Now I had two things in mind. I went home, I didn't tell to my wife, because that's the immediate person I had to tell. I knew she was expecting the worst from me, but I didn't tell her.

I said, 'Well the... what I did is that some of these tests which they have to do the second round so I haven't got the results.' So I had to wait until after Christmas. Yeah. So after Christmas then I tell. And obviously the other thing was to prepare her... And I, I just talked to her and said, 'Well, this is the situation.' And I knew the way she looked at me she, she wasn't shocked as such, but she just said that she suspected that was the outcome so... And again what I did was, because obviously I had expected that she may be in shock or something. But what I did was say, 'OK. I mean if it's...', I advised her actually, I said, 'If it's something you find very hard for you to take it, I wouldn't be sort of surprised if you think of leaving me, because I know HIV is something...'.

And, and then she said well, basically, because actually before we came, we had lost her mum from HIV. So basically, her mum and her young sister. So we lost from our family too, yeah. So basically what she said, 'Well, I've been this, I've been through this before, so why should I run away from you?'



And this is one funny thing I've found, men tend to, to sort of look to their peers. So that's where the, the likes of a support group plays a very magical role basically. Because we do tend to get men who perhaps... I mean I've met men who come to our support group who, who are not sure what is next.

But when they come to sort of the group, where there are other men, you know, they tend to treat that forum more or less like... it can be a religion. You know peer support, some kind of... so that's where they get strength... I mean, when you are a man or a boy in African setting, you know the, the men's club is really a cultural thing... that's where men get their own power, their, their, their inspiration, from their own groups.

And I think it, it... it, strangely enough, it seems to work quite well in the, you know even here (UK). Because even, you know when you meet men if the men are free then... If you go to a mixed group, where women and men are mixed, men are even shy to talk about their sexuality. How they feel about women. But where they, when they are together, they are very free to talk about sexuality, use of condom and all.

These extracts are from the DIPEX website. Copyright DIPEX. All rights reserved.

DIPEX is a charity that produces an award-winning website (<http://www.dipex.org/>) with video and audio clips from interviews in which people describe their experiences of health and illness. Unlike most web resources aimed at providing information and support, each DIPEX study is based on rigorous qualitative research. Participants are given a choice as to whether a video, audio or written version of their story appears on the website. They may also use a false name, or have their words spoken by an actor.

What is HIV?

HIV stands for Human Immunodeficiency Virus.

HIV infects and gradually destroys an infected person's immune system, reducing their protection against infection and cancers.

Initially, someone living with HIV may show no symptoms of HIV infection as their immune system manages to control it. However, in most cases their immune system will need help from anti-HIV drugs to keep the HIV infection under control. These drugs do not completely rid the body of HIV infection.

What is AIDS?

AIDS is short for Acquired Immune Deficiency Syndrome.

AIDS is not a single disease or condition. Instead, it is a term that describes the point when a person's immune system can no longer cope because of the damage caused by HIV and they start to get one or more specific illnesses.

People do not actually die from AIDS; they die from the cancers, pneumonia or other conditions that may take hold when their immune system has been weakened by HIV.

The term AIDS is now very rarely used. It is more usual to talk of late-stage or advanced HIV infection.

Source: <http://www.tht.org.uk/informationresources/hivandaids/whatarehivaids/>



Remi Al-Ameen

Remi Al-Ameen, Who am I? How does sickle affect me? How do I manage life, with Sickle Cell Anaemia? When I sat down to consider what someone might want to know when reading this spotlight, the above questions came to mind. Therefore I felt the best possible thing for me to do would be to answer them as briefly and directly as possible and without too much moaning.

First off then who am I? My name is Remi Al-Ameen and for the most part I try to live up to my name which when translated means friend of God, the trustworthy and the faithful. Although nobody is perfect, I am a trustworthy and faithful son of an Evangelical Christian mother and a strictly devout Muslim father. My age is a mystery, lets just say I am in my thirties and my age bothers me a little.

Most people know me through my work within the community. On various projects, in schools, college and most importantly the Youth Centre which has been running for a year and half now. I run a small charity “**Merton Youth Inclusion Trust**” . Actually this is a good point at which to start answering the question How does Sickle affect me? Sickle Cell has been around as far back as I can remember and since the day the doctors discovered that me and sickle were to be friends for life, it has been a roller coaster ride which has had some highs and for the most part very many low points.

Sickle hasn't done me any favours, in the physical department not that I'm not good looking or anything. Just that I knew from very early on that all this sickle stuff was going to mean curtains for severe physical exercise, in other words I wasn't going to be the next Daley Thompson or Linford Christie. Remi with a condition that at the time only a few people knew about. That is what I was going to be and nothing more. The Medical

fraternity have a way of reminding you that this was all you would be, however their words have had the opposite effect and in essence this has given me a sense of drive which has lasted the whole of my life.

In life we all face various obstacles some greater than others. My Sickle has given me the drive to do some innovative & quite remarkable things. Moving at a fast pace wondering whether my life would end tomorrow or not, has had its setbacks. Some people cant keep up with my "it should have been done yesterday" mentality. Others congratulate me on my drive, persistence and determination. The only way to describe it is that it feels as if you are playing a board game and just before you get to the end the dice, pieces and the board will all disappear so you better play fast or else you will miss out.

How do I manage life, with Sickle Cell Anaemia?

Having spoken about this at length, my understanding is that as Sicklers we need to embrace the way we live, understand our limitations and take it easy because we will all die someday. Beyond this, with Sickle you take every day as it comes, we all know that we shouldn't be cold, stressed or dehydrated. But we still get ourselves into it.

Do make sure that you enjoy every precious moment of this life and Yeah do things that will precipitate the cold, stress and dehydration!! I do frequently. This is the only way I cope with things. As for painkilling, until they invent a painkiller that doesn't make you feel like a junkie, and is as natural and homeopathic as some of the remedies out there I will be managing the minor crises with mind control and the major crises at hospital.

"This article was first published in September 2005 on the MSCTG (Merton Sickle Cell and Thalassaemia Group) website. It is Copyright MSCTG. All rights reserved" <http://www.msctg.org.uk/Spotlight.htm>

What is sickle cell disease?

Sickle cell disease changes normal, round red blood cells into cells that are shaped like crescent moons. The name “sickle cell” comes from the crescent shape of the cells. A sickle is a farm tool with a curved blade that is used to cut crops like wheat.

Normal red blood cells move easily through your blood vessels, taking oxygen to every part of your body. But sickled cells can get stuck and block blood vessels, which stops the oxygen from getting through. That can cause a lot of pain. It can also harm organs, muscles, and bones.

Having sickle cell disease means a lifelong battle against the health problems it can cause, such as pain, infections, anemia, and stroke. But many people are able to have a very good quality of life by learning to manage the disease.

Sickle cell disease is inherited, which means it is passed from parent to child. To get sickle cell disease, a child has to inherit two sickle cell genes - one from each parent. Sickle Cell Disease mostly affects people from the African, African Caribbean, Italian, Greek, and Arab communities. (Where Caucasians, Asians and Europeans have inherited this defective gene, it is not necessarily a result of being from a mixed African or Caribbean background.) Thalassaemia mostly affects Asians, Greeks, Italians, Africans, as well as Caribbean and Hispanic communities.

When a child inherits the gene from just one parent, that child has sickle cell trait . Having this trait means that you do not have the disease, but you are a carrier and could pass it on to your children.

Painful events are the most common symptom of sickle cell disease. They are periods of pain that happen when sickled cells get stuck in blood

vessels and block the blood flow. These events usually cause pain in the hands, feet, belly, back, or chest. The pain may last for hours or for days.

People with sickle cell disease often have anemia , caused by a shortage of normal red blood cells. Anemia makes you feel weak and tired. People with sickle cell anemia may look pale or washed out. They may have a yellowish look to their skin and the whites of their eyes (jaundice).

Doctors cannot yet tell which symptoms a child born with sickle cell disease will have, when they will start, or how serious they will be.

A simple blood test can show whether a person has sickle cell disease. ...

Early treatment includes daily antibiotics from 2 months to 5 years of age to help prevent infections. Routine childhood immunizations are also important.

Managing pain is often a big part of having sickle cell disease. ...

Some people need regular blood transfusions to keep down the number of painful events and lower the risk of stroke and other problems.

Regular checkups are an important part of life with this disease. People with sickle cell disease need a good working relationship with a doctor who is an expert in treating it.

Source: <http://www.webmd.com/a-to-z-guides/Sickle-Cell-Disease-Topic-Overview>

MS: The 'white man's disease'

by Sarvat Khan

Sarvat Khan lives in Lancashire. She was diagnosed with Multiple Sclerosis (MS) eleven years ago. The two-lettered condition is not common across the globe meaning her family and local Asian community often find it hard to get to grips with what's happening to her.

My father took me to see his doctor - Dr P - in 1996 because the diagnosis I had received from my neurologist was alien to him. The GP told us both that that I couldn't possibly have Multiple Sclerosis because it's a "white man's disease".

Is it? Why? Did that mean I had been misdiagnosed?

The mixed messages made me start me researching the disease, and I discovered that MS is a condition predominately found in temperate latitudes. The majority of carriers reside in the western hemisphere. The disease is most common in Europe, North America, Australia and New Zealand. Those areas north of 40 degrees latitude have a higher occurrence than those around the Equator. All this supports the theory that MS is predominantly a disease affecting northerly countries.

So, how prevalent is it in India and Pakistan? It's not true to say it's unheard of. Though it is uncommon, there are some cases of people with MS and I did come across a branch of the MS Society in Karachi.

On the whole MS is rare in this part of the world due to a combination of geography, diet, medical facilities and lack of financial resources to diagnose the disease - the NHS is but a dream for these people.

For the average person the facilities are non-existent. For medical matters they are often seen by Moulvi's - religious priests. Prayers will be made for the patient, two things would be suspected: either evil spirits or black magic - that's another story!

To obtain a diagnosis of MS, you either need a lumbar puncture or a MRI scan - both of which are not common or not accessible. Although Karachi has a scanner, for instance, the cost of a diagnosis can extend into thousands of Rupees, the kind of money only the very wealthy have.

Some theorise that sunlight and seasons are possible factors in the occurrence of the disease. Research shows that disease onset and relapses are more common in the springtime and less common in the winter. The variance between the seasons is more prominent in areas further away from the equator meaning MS symptoms might be more extreme or noticeable further north.

Another possibility is diet. MS in the coastal regions of Norway is lower than the rest of the country. Could this be due to the higher-level of fish consumption? Fish apparently is high in Vitamin D3 and Omega-3 fish oils; one or both of these facts may play a part.

In my own experience I have not come across a member of the Bengali community suffering the disease. Could this be due to their staple diet of boiled rice and fish?

So why have I got it? Could genetics play a role? MS is particularly common within people of European origin, especially British and Scandinavian. It is rare in Chinese and Japanese people, who often suffer a more aggressive form of the disease if contracted.

Does the fact my father migrated to England in 1960 hold the key to my MS? According to one study, migrating from one area of the globe to

another before puberty means that the individual takes on the incidence of the area to which they migrate.

First generation immigrants to Britain have a much lower incidence of MS than their second-generation counterparts. Something I'm sure no one considered when migrating. What was often unheard of in the Asian community is now affecting more Asians year on year.

Awareness of the disease in our community is gradually increasing, more and more cases are surfacing. I was fortunate enough to be put in touch with a group that is a spin off from the MS Society and closer to home for me - the Asian MS Society. They deal with the unique problems facing members of our community.

Trying to explain my diagnosis to my parents proved extremely difficult. I felt as though I was dealing with and accepting the diagnosis easier than they were. It must be frightening knowing that your youngest child has a disease you have never before heard of. Fortunately the Asian MS Society provided a number of useful articles in Urdu. Allowing my parents to gain a better understanding of what MS is and how it can be managed.

At the time they were adamant that I was never to let anyone know of the diagnosis. Disability is often something that Asians feel ashamed of and brushing it under the carpet is a natural reaction. As time passes, my parents and others have come to accept my illness as they learn more about MS and challenges it poses to both able-bodied as well as disabled people.

The numbers are creeping up as more Asian MSers brave the stigma attached to having a disease and 'out' them. Females are affected more than men on a two to one ratio. I was told just last week of a young Asian girl recently diagnosed who had been told by her parents never to let

anyone know in the fear that she wouldn't find a suitable marriage partner. The sad fact is very few Asian parents would ever let their children marry a person who suffered with a chronic disease that has such an unpredictable nature.

Going back to my father's GP, Dr P, I saw him at Tesco three months ago. I was shopping on my scooter as usual. He hadn't seen me since telling me I would wake up one day and it would be gone. Poor guy looked as though he had seen a ghost; he couldn't even look me in the eye. Ironically I am now good friends with his daughter, who was diagnosed with MS a few years ago.

"This article was first published in 2006 on Ouch! - bbc.co.uk/ouch - the BBC's disability website. It is Copyright BBC. All rights reserved"



What is MS?

Multiple Sclerosis (MS) is the most common disabling neurological condition affecting young adults. Around 85,000 people in the UK have MS. MS is most often diagnosed in people between the ages of 20 and 40 – though it can be earlier or later. Women are almost twice as likely as men to develop MS, and in rare cases it affects children.

MS is the result of damage to myelin - a protective sheath surrounding nerve fibres of the central nervous system.

When myelin is damaged, this interferes with messages between the brain and other parts of the body.

For some people, MS is characterised by periods of relapse and remission while for others it has a progressive pattern. For everyone, it makes life unpredictable.

Once diagnosed, MS stays with the person for life, but treatments and specialist care can help people to manage many symptoms well. Although its cause is not known and a cure has yet to be identified, research continues into all aspects of the condition.

Source: http://www.mssociety.org.uk/about_ms/index.html

Breaking it down: Mental health and the African community

Me2We - Mental Health

Mon 18 December 2006

Morenike Fasuyi discusses her personal experience within the British mental health institutions and highlights the need for the government to honestly address the serious issue of mental health and the African community in the UK.

Dealing with the pressures of life in the United Kingdom as an African person is extremely difficult. The general consensus suggests that African people have to work twice as hard as their European counterparts in every aspect of our social, cultural and economical existence in order to make ends meet.

Coupled with the covert oppression exhibited by the powers that be, we also have to contend with the difficult issues that manifest in our relationships, marriage, family and work. The accumulation of the above factors, of course leads to stress. In some cases, the stress levels are so high that you end up having a nervous breakdown. I should know because I have been there.

I am not ashamed to express my views on this matter. I believe that my experience should be shared in order to inform some of you that anybody can break down at anytime and remind those who have gone or are going through similar experiences that you are not alone. I have positively been able to identify my experience as a journey. The views I hold are based on my local health authority and what I have experienced, others health authorities may be different.

One minute I am a successful individual, reasonable income and full of confidence. The next minute, at the age of 31, I was diagnosed with Bipolar Affective Disorder. This is a condition where your mood can go between extremes of high to low causing you to act in ways that are out of character. Another term for the condition is manic depressive. I still have reservations about the diagnoses as I am against the mental health profession attaching labels which ultimately define you. Thus you become part of the system.

The reason I hold this view is because my Bipolar is triggered and predominately based around African issues, such as slavery, politics, oppression, Africa and the suffering of my brothers and sisters in the Diaspora. I suffered from flashbacks as to what it would have been like for our brothers and sisters on the boats, shackled and naked. I imagined the stench, as where they lay, was where they released all bodily functions. Imagine the Women during their menstruation... I imagined their screams in their African dialect shouting 'Oyinbo bo, Oyinbo bo, sa re sa re!' - The white man is coming run run!! - in Yoruba Dialect. I would get flash backs of how they were taken off the ships shackled, soiled naked and cold. When we are cold, we have the luxury of wearing jackets or coats and we as African people, are still cold!!

Basically my condition takes me back to the time of enslavement. I feel the pain, sorrow and suffering and the obvious hatred towards Europeans. I begin to get agitated and unable to cope with the reality of what has happened and what continues to happen in the world pertaining to African people. I feel hopeless and scared because we are still experiencing the effects of our enslavement. This is not to say, that there are no successful African people in the world, however the ratio is very unbalanced and it is time that we united as a mighty African race. I feel that there appears to be

a concerted effort by Western Governments to keep African people oppressed, through neo-colonialism and indoctrination.

My feelings are anxious and grandeur, which is not a crime. My condition encourages me to push for change now as the exploitation and oppression of African people globally has gone on long enough. As a campaigner, naturally I want action now. We have been going to meetings upon meetings, talking for the past 50 years about the struggle yet we are still fearful of moving forward. This feeling also affects my wellbeing. The only individual in my opinion, who courageously fought for the rights of his people through his ideology of how we emancipate ourselves economically and culturally, was Marcus Garvey.

On May 1st 2004, I awoke from my bed and screamed "Oh my God" - I can only explain it in spiritual terms. It was as if the ancestors called upon me and removed the scales from my eyes. I was able to see the ugly world we live in and the high level of conspiracy that has been logistically planned to avoid a potential African "Revolution". Karl Marx discusses this pattern when he talks about groups that are oppressed eventually gaining a class consciousness that ultimately leads to a revolution.

May 1st is where my journey began. I became overwhelmed with a spiritual understanding of numerology and how numbers relate to African people especially the numbers 7 and 9. I also felt alerted to the fact that 2007 may be the year that could potentially homogenize the divisions within the African community in order to effect change. There was also a strong sense of acknowledging, 'European Envy' towards African people which has historically continued to fuel their oppressive practices.

With all these thoughts going on in my head I could not sleep. In fact, I did not sleep for three days. I called a friend to come to my aid as I did not know what was happening to me. My views about the ancestors, African

history and politics caused concern for my family and friends. I was concerned myself! And this is how I gained my pass into the British Mental Health system.

Tactics

The mental health system is killing us point blank. If you are not strong, the system will break you down, so that you fit the part of looking dishevelled, impoverished and “mad”. In some cases, your family, although unconsciously, will hand you over to the system as they do not have the knowledge to understand what is really going on. This is why you see many brothers and sisters looking rough in the street, hair uncombed and with poor personal hygiene. Families tend not to ask relevant questions or challenge the practices of hospital consultants and doctors. In some cases families neglect that the member of their family who has mental health issues.

Maintaining you within the system keeps consultants in their jobs and increases the profit of the pharmaceutical industry, which has a turnover of billions. I met a patient who had been in the hospital for five years! To me this was negligence on the part of the system since it is a statutory requirement for patients to have a structured care plan, social worker and other support that would involve care in the community - What were they doing for this patient who actually lived in the hospital?

Another tactic used to undermine you is intellectual intimidation.

Consultants and doctors discuss very complicated clinical issues with patients who are incapable of understanding what is actually being said. This method of complicated jargon is also used when they talk to relatives, leaving everybody somewhat confused and resigned to the fact that the system knows best.

To further reinforce this point, in The North Kensington hospital where I

was, they organize weekly meetings with patients. This is called ward round. You basically have to sit before a panel of consultants, doctors, student doctors, pharmacists, social workers and therapists. You are asked questions about how you feel and they discuss medication whilst you are being assessed. This particular forum is very intimidating, especially if you do not have the ability to articulate yourself in the same manner in which the panel addresses you. And if you are drugged up, you stand no chance of making sense which ultimately means you will not be able to justify being released from detention. I found these meetings pointless as they never wanted to hear about my condition being connected to cultural, spiritual and political issues. I was just seen as being a Bipolar sufferer... end of story.

When I tried to introduce the diagnoses of Post Traumatic Slave Syndrome by Doctor Joyce Leary, which has been recognized as a medical condition in the United States, I was basically digging myself into a grave, as this assertion of mine, meant that I was unwell! I showed them the book, I read out symptoms, such as:

- Difficulty falling or staying asleep
- Irritability or outbursts of anger
- Intense Psychological distress at exposure to internal or external cues that symbolize or resemble a traumatic event, (Slave Trade)
- Feeling a detachment or estranged from others

All of which I identified with!

The mental health system in the UK is so rigid and based on discriminative European ideology that they will never accept Post Traumatic Slave Syndrome as a clinical condition. You are either

schizophrenic, psychotic, bipolar and many other mental labels they have theorized, but you can not have a condition that manifests from a cultural or spiritual dimension.

The National Institute for Mental health in England conducted a study March 2003 entitled 'Inside Outside: Improving Services for Black and Minority Ethnic Communities'. An overwhelming 66% of African people complained of discrimination within the mental health services. The Delivering Race Equality in Mental Health Care Booklet, stipulates, "There should be ministerial acknowledgement of the presence of institutional racism in the mental health services and a commitment to eliminate it"... yea right!

Druggies

They pump you up with drugs many of which have side effects such as hallucinations, impotency, muscle spasms, memory loss, obesity... the list is endless.

The administering of the medication makes their jobs a lot easier because the medication sedates you. This is why we see some of our brothers and sisters walking around like zombies with very slow physical motions and speech delivery.

Medication is also administered as soon as you wake up in the morning, drowsy from your sleep; you are already sedated before 9am! I had to be strong. I had to adopt warrior like principles to address the medication as mind over matter. One positive thing that I instigated is that I told all the patients to get information about their medication as they had a right to do so. I always tried to empower them because these were my brothers and sisters caught up in the system with bleak prospects and no hope.

I found, that once you are in the system possibly under a section 1, 2 or 3,

mainly section 3, which, can keep you in hospital for 6 months for assessment and “treatment” you have no power whatsoever, patients become very institutionalized and reliant upon the system.

Another aspect of their practices which concerned me was that if you refuse your medication, you are forced to have an injection. If you were agitated or questioned their motives in a passionate way, you are seen as aggressive and given an injection.

Some of our brothers and sisters at some stage of their treatment are introduced to regular injections, this method is called being on ‘Depo’. This is to ensure that you are medicated and drugged up to the eyeballs - in many cases, for life. It’s funny how the system is hell bent on administering medication but yet people are still being admitted and readmitted to hospital suffering from the same symptoms... this begs the question, what does the medication actually do?

Overrepresentation of African people in Britain’s mental health system

More than 80% of patients in psychiatric wards are African. This is a fact that the government has recognized and has always known. I have only come across a few European people in the mental health system and when I have, their mental condition always seemed to be more severe than those of African patients. Some of them tie ligatures around their necks to kill themselves, others mutilate their bodies with sharp objects or burn themselves with cigarettes. I was scared by this as I had never seen it before in my life. When I would ask them why they do it, their reply was always that the Devil tells them to do it. Some of them admitted to worshipping the devil which triggers off their mental illness.

However, African people are more likely than Europeans to be given a clinical diagnosis that warrants medication, intervention and detention

under the Mental Health Act 1983. The death of David Bennett in 1998, who died in a secure unit as a result of being restrained by practices that were beyond procedure, instigated an independent inquiry into his death and the discriminative nature of the mental health system in general. The government issued recommendations that all Mental Health Authorities should follow in order to deliver equality in mental health care.

The 'Delivering Race Equality' report published in January 2005 stipulates:

- There should be a reduction in the disproportionate rate of admissions of people from BME groups – (Black Minority Ethnic)
- A reduction in the disproportionate rates of compulsory detention of BME users in inpatient units
- Increased satisfaction of services
- A more balanced range of effective therapies other than medication, support services counselling treatments as well as pharmacological interventions that are culturally appropriate and effective.
- The Government also recommended that all NHS staff involved in mental health should undertake a course called Cultural awareness and sensitivity training.

All Talk No Action

The report and its recommendations are just words. The various training strategies for NHS staff members to be aware of the cultural needs and differences of service users are not working. Whilst in hospital, I conducted a mini research by asking nurses, consultants and doctors if they had been on any cultural awareness training. Out of 15 staff members only 2 had attended the training. Most of them had not even heard of it or read the independent inquiry into the death of David Bennett.

Further recommendations stipulated that there should be a National Director for Mental Health and Ethnicity. National Directors should be appointed by the Secretary of state for health to oversee the improvement of all aspects of mental health services to the African community. A Professor Kamlesh Patel has agreed to lead the Departments programme of action and chair its 'BME' Mental Health Programme. My concern is what does an Asian man know about the serious cultural and social issues that continue to affect the African British community, causing stress and mental health problems?

We have Lord Victor Adebawale, the chief executive of Turning Point, who will advise the national steering group on relevant issues. I question what he has done thus far and whether he has made any adequate recommendations. I would advise him to visit St Charles Hospital in North Kensington to check their race equality plan and commitment to the government's recommendations.

We have the CRE, the Race Relations Amendment Act (2000) and a plethora of groups, committees, national bodies, recommendations and statutory requirements and yet we have failed to make any substantial progress with a smoke screen shielding the pure, unrelenting discrimination!

No Cultural Awareness and Discrimination

Not once did anybody take out the time to sit down with me to explore why I have these episodes and their cultural content. I asked to be referred to an African psychiatrist who would be able to understand some of my issues. This was a slow process as I was also told there are hardly any. I feel that if they looked hard enough, they would have found one. It all comes down to resources and limiting the funds that are awarded to the African Mental Health community.

I finally managed to get a counsellor through the Oremi organisation in North Kensington who do a fantastic job of rehabilitating African mental health service users on a small budget! I also asked for an African social worker but instead they gave me an insensitive male European social worker who adversely affected my health with his actions, racist remarks and incompetence.

The British Mental Health System has no real interest in understanding the core root of African mental health issues which are predominately caused by issues relating to socio-economics, cultural identity, employment, racism, oppression and learning the historical facts of African Evolution.

The system is not interested in how brothers and sisters became the way they were or what the triggers are. They are more concerned with medication and sedation. Whilst I was in hospital, I observed things that were completely discriminative! For example, the ward issued small thin tooth European combs for everybody with no regard as to how these combs would be used by African patients with afro hair texture. This is why you see some brothers and sisters walking around with their hair always in a mess or even matted. Patients are not encouraged or supported to address their personal care and hygiene. There was no body lotion on the ward suitable to moisturize African skin and as a result some patients had to walk around with dry, flaky skin. In addition, there was no hair grease, no deodorant and cheap shampoo that resembled washing up liquid and was not at all compatible with African hair texture. These observations were particularly painful as so many inpatients have issues around abandonment. There is no family member to say "fix up, look sharp". Thus they end up looking the part and playing the role of the "Mad Man" or "Mad Woman". There was no implementation of an efficient equality action plan or a commitment to addressing our "cultural needs".

African Staff without a Clue!

The most astonishing thing about the ward that I was on was that the manager was an African woman! Another observation is the overrepresentation of African mental health nurses who are not doing the job for the love of people. They have no sensitivity to what is going on regarding their own people. It is as if they are simply and mindlessly carrying out the masters orders. Many of them will tell you that there is no such thing as racism or discrimination! Despite the negativity of some staff members, there are also African people who work in mental health who actively challenge the discriminative practices of the mental health system.

Be Real

There is so much going on that needs to be addressed once and for all. Despite government recommendations and the announcement of £510 million being injected into mental health over the next 3 years, to add to the existing £180 million, there is still a lack of acknowledgement of the cultural needs of African patients. We are still exposed to serious insensitivity, labelled as aggressive, marginalized and severely discriminated against. The system still simply does not understand African culture, spiritualist identity, mannerisms and the issues that come with being African.

The Department of Health and the British government are still failing our people in mental health and there appears to be no intention of addressing the inequalities ranging from diagnoses, detention, sectioning and medication. I feel that we need to establish a grassroots African Mental Health Body that has the capacity and ability to consult, advise and make recommendations on any issue that concerns African people and the mental health system, and then maybe we can fix this mess.

This article is from the Ligali Media Network

<http://www.ligali.org/article.php?id=590>

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For an explanation of what bipolar disorder is from Mind's information booklet, click on the following link:

http://www.mind.org.uk/Information/Booklets/Understanding/Understanding+manic+depression.htm#hat_is_bipolar_disorder_manic_depression



Success Stories of Persons with Disabilities in Afghanistan: United Nations Development Programme

Qudsia Zohra Dastgir is 19-years-old. Eight years ago, she lost her right leg in a rocket attack in Kabul. During the time of the Taliban she was not able to attend school but received home education on a variety of subjects, including English and computer skills.

Once she was able to proficiently read, write, and speak English, she began teaching the language to nurses working at the orthopedic center established by the International Committee for the Red Cross (ICRC). After the collapse of the Taliban, she got a job in the main delegation of the ICRC in Kabul and has been working there ever since. She says she is “dreaming of a day when everywhere in Afghanistan is wheelchair accessible.”

She is currently working part-time and finishing high school. After graduating with a diploma, she plans to study law to “help persons with disabilities enjoy their rights.”

Backtosh Naasrat was born in Panshir province. During the rule of the Taliban government, Backtosh, who is hearing impaired, went to Tajikistan and spent nine years there. While away from his homeland he learned how to read and write in Russian and to communicate through the Russian Sign Language. He also took an interest in learning taekwando and trained in a martial arts academy for four years.

When he returned to Afghanistan, he began learning the Afghan Sign Language and opened up a taekwando club. He has recently started volunteering with the special education unit at the Comprehensive Disabled Afghans’ Program, working with hearing impaired children. Backtosh

teaches them taekwando as part of their physical education and encourages their involvement in other sports activities.

Ibrahem is 10 years old and lives in a village that is far away from the city. He has polio and his leg muscles are very weak. When he was younger he could not sit nor walk. He felt very hopeless because of his disability.

When Ibrahem was five years old his parents learned about an organization working for persons with disabilities, offering free rehabilitation services. His parents took him to the center set up by Sandy Gall's Afghanistan Appeal. At the center, they taught him physiotherapy exercises and once his leg was ready for the proper appliance, they introduced him to an orthopedic workshop and gave him equipment that helps him walk on his own. In the past he relied on his parents and younger brother to carry him. He was often bored and felt helpless. Today Ibrahem is much more independent and happy. He attends a public school where he has made friends his age and is learning how to read and write. He wants to become a teacher and educate other children with disabilities.

Abdul Ghaffar was born in Kabul in 1977. When he was three years old, he had an accident, which damaged his hearing. He says this altered his life greatly and despite his family's efforts to cure him, they were not successful.

During the Russian invasion of Afghanistan, Ghafar and his family fled to Pakistan. "I don't know how to express those horrible days and nights which we spent in Pakistan. While living in Pakistan I faced many problems and often felt like an outsider because of my inability to communicate," he says.

Ghafar was unable to attend school because instruction in sign language was not available. Eventually, his brother found a school where he could

study, but the school was far away and due to economic constraints he could not afford public transportation, so he had to walk long distances everyday.

After graduating, he met a foreigner who for three years taught him how to read and write English. Soon after Ghafar was hired by Serving Emergency Relief and Vocational Enterprise (SERVE), a non-governmental organization working in the disability sector in Kabul and Jalalabad.

“The time I was working with SERVE was when the Taliban was in full power in Afghanistan. I confronted much hardship during the regime of the Taliban. For example I was put into jail because I was accused of having connections with Arabs,” he says.

Since the fall of the Taliban, Ghafar began working with Comprehensive Disabled Afghans’ Programme as an educator for people with hearing impairments. He is also an active member of the Afghan National Association of the Deaf and is working on a committee responsible for developing 2,000 new words in the Afghan Sign Language.

Source: <http://miusa.org/publications/freeresources/mti/chapter13>

Tamanna's story

Tamanna Choudhury is a 31 year Self-Advocacy Development Worker for the charity People First. It is her first paid employment, achieved with the backing and support of Shaw Trust. Tamanna has overcome a series of difficulties which she has refused to allow to dictate her life and the choices she makes.

Barely a year ago, Tamanna Choudhury was very nervous of travelling on the tube alone, hated standing up and talking to groups of people and hardly dared believe she would one day have a fulltime paid job. Today she travels all over the UK by train and plane, and in the course of her fulltime work addresses groups of up to a hundred people at a time.

There has been [no] amazing personality change here, just plenty of support and a steady determination to grab the opportunities offered and make the best of what came her way. "I was so nervous at first but I had to overcome my fears and now I'm very proud of the situation I'm in," says Tamanna.

Tamanna has learning disabilities. She also has mobility problems, has suffered with depression and is on medication for epilepsy. But none of these have stopped her achieving her ambition – to find full-time paid employment. "I spent nine years doing all kinds of training and education courses and part of me never thought I'd achieve more than that. But I always wanted to work and this job is about helping people. It's made a big difference to me being able to help others," she said. Her work as part of a National Self- Advocacy team means offering advice and information to some of the 133 groups across the country from Coventry to Bournemouth, Berkshire to Belfast.

"Self-advocacy groups are very, very important to people with learning disabilities. They are the only opportunity for people to talk about issues they can't bring up with their families or others."

“I am the only person in my family with learning disabilities and I feel very strongly about the subject.”

David Hamilton, Shaw Trust Officer for north-west and west London who supported Tamanna into employment is proud of Tamanna’s achievements. “She has overcome so much in the last ten months and done really well. She lacked confidence so we helped her with some travel training, her job application and interview presentation and bought her a laptop to help her in the job,” he said.

“I just try to do my best and take one day at a time. And put my faith in God,” added Tamanna, whose Muslim faith is very important to her.

Tamanna is also helped by being surrounded by like-minded and supportive colleagues, at People First.

“This organisation is solely run by and for people with learning disabilities,” says People First Director Andrew Lee, the first person in the UK with learning disabilities to hold such a post. “Most people with learning disabilities find a voice through their local self advocacy group, as did Tamanna. In helping people find a voice, these groups also help people find a way into the world of work.”

Tamanna admits she has come so far so fast in the past year she has overtaken her own ambitions. “Getting a job was my ambition and I’ve achieved that, which is great. I don’t know what else may lie ahead. I’d just say to anyone who has dreams they should never give them up but keep working to achieve them. Don’t be put off by anything or anyone.”

Tamanna was supported into employment via Shaw Trust’s Workstep programme in London. For more information please call Shaw Trust FREE on 0800 085 1001.

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Raymond Johnson, People First, London

Raymond Johnson, took part in the Disability Rights Commission's 'Taking the dis' awareness-raising campaign. Raymond works at People First.

Where do you live?

I live in Wood Green, London. I've lived there for the last eight years. I live in a council flat on my own.

How do you spend your free time?

I like surfing the internet and going to football matches. I go to see Leeds United play – I've held a season ticket for them for many years. Elland Road is a great stadium; I go up with the London branch of supporters. We hang around the city and go for a few drinks before the game.

What are you most proud of?

Getting the council flat I wanted. It was quite difficult; the council could be quite slow. But having gone from shared accommodation to my own flat was good.

What is your job at People First?

I work at People First (Self Advocacy) in London. I'm the office manager, and we've got another guy with a learning disability, Andrew Lee, who's the director. Between us we run the organisation. We've got some supporters who help us, but we don't rely on them to take over. I go up and down the country to see other People First groups and help them set up self advocacy.

Who are your heroes?

I'd have to say Linford Christie. He's an excellent athlete. I think he's done really well for athletics. Also, the guy in the wheelchair who has a physical disability and is on the BBC adverts [Ade Adepitan]. He's a basketball

player and was in a programme called Beyond Boundaries. I met him once or twice. He's really interesting and friendly.

You're involved in the Disability Rights Commission's 'Taking the dis' campaign. How did this come about?

I've been discriminated against a number of times. A woman serving me in a cafe was ignorant when she spoke to me. Because of the way I spoke she made assumptions that I was drunk. I've been telling the Disability Rights Commission about my experiences to help them with their campaign on discrimination.

Do you think that more people with a learning disability should be in high positions like you?

Definitely. Mainly people just get a job packing boxes of peas or something – the money they give you is peanuts. We're in the 21st century and it's important to tell parliament to stop discrimination.

What changes would you like to see made to help people with a learning disability?

I think I'd get rid of day centres. The people that run them often don't think about people who have learning difficulties. The ones that I've been to do not cater for black and ethnic minorities with learning difficulties.

"This article was first published in 2006 in Viewpoint, the learning disability magazine published by Mencap. It is Copyright Mencap. All rights reserved".

Richard West

Richard lives in London. He has a learning disability and a hearing impairment and is also a full time carer. He became interested in the arts through college courses and community arts for disabled people. He started his career in the early 1990s in a theatre show called Summertime, which was performed at the Young Vic. He became an artist with renowned arts organisation Heart 'n Soul and with them has gone on to work as an MC, DJ and VJ, using computer technology to mix music and video. He has worked with them and independently all around the country as a DJ and VJ and has even been as far as Berlin. He has also worked as a consultant, sharing his knowledge and experience with people all around the UK hoping to get involved with learning disability arts.

He has been involved with many organisations, campaigning for and advising on better access for learning disabled people, including Change, Artsline, Mencap, Arts Council England, Department of Transport, the Care Standards Commission and the Department of Health. He played a big part in many important advances and conferences for and about learning disabled people including the Change Picturebank project to make information accessible and more recently with Valuing People, the government white paper on learning disability.

He has a passion for Carnival Arts, taking part in many Notting Hill Carnivals and Thames Festivals and in 2008 will take part in the Luton and Rotterdam Carnivals. He is also part of the organising committee of the Oska Bright Film Festival, a short film festival by filmmakers with a learning disability, run by Carousel Arts.

Richard says

“The Beautiful Octopus Clubs [nightclubs designed and run by and for people with learning disabilities] are a great place to go night clubbing if you are a person with a learning disability. It is also accessible for a Deaf person with learning disability.

I do a lot of MC-ing and making people very welcome with laughter. I am a very good DJ and quite a famous person in the arts world. I go to lots of different arts meetings for Heart ‘n Soul, sometimes I do a lot of training for different people. I also helped Heart ‘n Soul in making the web site accessible.

My favourite part was going to Berlin with Hannah Marvally. This was part of the Disability Arts festival in 2004. We didn't leave the nightclub until 4.30am and it was lots of fun! What makes it so good – we were at the time the only two people with a learning disability to DJ at a mainstream nightclub in Europe! I think other clubs should follow our example!! Heart ‘n Soul has given me the chance to do what really interests me, and gives me the chance to learn and explore new things.”



My amazing day (the day I met Nelson)

by Lizzie Emeh

I live in a very rough part of London (the wrong end of Ladbrooke Grove). I was born round here. I was plodding along in life, nobody noticing me – nobody saying look you've got a talent - use it. I went to a mainstream school; I went to a special school with people like me (with disabilities)

When I turned 19, I tried living in a residential place in Earls Court. I was still plodding along – and then a very significant thing happened in my life. It brought a lot of pain - when my Nan died.

But just at the same time another door opened. I went to the Heart 'n Soul (HNS) Beautiful Octopus Club – a nightclub that was run by people like me - the minute I walked through those magical doors all my pain vanished! The moment I got on that stage for the Open Mic slot, my disability disappeared and I was in my own type of world – when I am on that stage I don't focus on anything else– I am who I am on that stage – you just take me as I am. Mark Williams (HNS Director) came running up to me and said I want you to be in Heart 'n Soul. I said what me – no surely not! I went to an audition – quietly confident and did my thing – at the end Mark turned to me and said – 'you're in!'

From that moment my life totally and utterly changed! I was able to write and perform my own songs and really express myself. Heart 'n Soul has made people notice me, and I've got their respect now. It's been a long time coming but eventually I have got people's respect. When I was singing before, they didn't used to listen to me but now they come and see the shows and say to me: 'You're really, really good' and 'Wow that was amazing; your voice is just amazing'. I turn round and say it's a gift and I use that gift. Everyone else has got a gift.

And then I had the chance to be invited to be a spokesperson for the Princess Diana Memorial Fund who were supporting Heart 'n Soul. We did some media training, and after that I went on London Tonight on the news. There was another total big turnaround when I got the opportunity to meet Nelson Mandela at Althorp, where Lady Diana is buried.

When Mark told me that I was going to meet Nelson Mandela, my legs turned to jelly and I slipped to the floor - I said what do I say when I meet him? Mark said -“hello would be a good start!”

When I was coming home I phoned my mum and I said guess what – tomorrow I am going to meet Nelson Mandela – she said what – you’re kidding me – **the** Nelson Mandela– that’s amazing! She was screaming down the phone - she was as excited as I was!

The next day I met Mark at Euston station – there were a few other spokesperson people who were chosen – a select few were with us. When we were on the train it didn’t really kick in – everyone was asking me “are you ok” cos I was really quiet – I was trying to keep myself composed and steady. When we got to Althorp I turned round and I said to Mark – ‘tell me this is a dream’ - he pinched me and said “you **are** going to meet Nelson Mandela”.

We went in to a great big hall for lunch, - we ate with Nelson Mandela’s’ security team - after that we all went out into the garden, by the lake where Lady Diana was buried. This black 4 x 4 pulled up driven by Earl Spencer – sitting in the back was Nelson Mandela.

It was a lovely typical English day – raining as usual – you get the President of the ANC coming to England and what does it do? It rains!

He pulled up, walked out of his car – he turned round and said “it is a honour and a privilege to meet you”. In my head I felt it was the other way round – I couldn’t say that to him though!

He shook my hand – did you know Nelson Mandela is very funny? He turned round and said you know I’ve got some grandchildren at home – why don’t you and your friends come back to my country and pick out a husband and wife for each of you! It felt totally amazing, minted!

If I can get to meet Nelson Mandela, then I am sure that I can achieve absolutely anything in my life.

In the future I would like to do other things. I have a really big ambition for a person who has a learning disability. I would like to be presented with a Music of Black Origin (MOBO) Award for my work – I could really see myself on that stage. But I wouldn’t be picking up the award just for myself; I would be picking up the award for people with learning disabilities too. Nelson Mandela did things to help other people. If you can do other things to help other people the world would be a better place.



What is a learning disability?

A learning disability affects the way someone learns, communicates or does some everyday things. Someone has a learning disability all through their life.

There are many different types of learning disability. They can be mild, moderate or severe.

Some people with a mild learning disability do not need a lot of support in their lives. But other people may need support with all sorts of things, like getting dressed, going shopping, or filling out forms.

Some people with a learning disability also have a physical disability. This can mean they need a lot of support 24 hours a day. This is known as profound and multiple learning disability (PMLD).

A learning disability does not stop someone from learning and achieving a lot in life, if they get the right support.

Here are some important facts about learning disability:

- 1.5 million people in the UK have a learning disability.
- 200 babies are born with a learning disability every week.
- 9 out of 10 people with a learning disability get bullied.

There are more than 29,000 people with a severe or profound learning disability who live at home with carers aged over 70.

Source: http://www.mencap.org.uk/html/about_learning_disability/what_is_learning_disability.asp

Baruch's Bar Mitzvah

By [Sara Rosenfeld](#)

I never would have thought that I would have written a story about Baruch. But I did, and it has been one of the best things I have done. Little did I know that one story, my personal experience, could affect people in the way that it has. Little did I know that it could affect me in the way that it has.

When that article was posted (See, [Baruch, Our Special Child](#)) I showed Baruch the picture of himself that accompanied the piece. The first thing he did was point to his picture and then point to himself (means "me") and then he saw my name and signed 'good' and gave me a big hug! I took this as my personal sign from G-d that I did the right thing in writing that story.

It was because of that story that I am now writing this one. I am grateful to all who read about Baruch and were concerned and connected and inspired me to once again write about him.

As you know, Baruch is not the ordinary kid next door. Baruch is truly a miracle child. He was born with severe disabilities that caused other infections and problems so that much of his first few years of life was touch and go. We lived with the knowledge that at any moment our precious boy could be taken from us. And yet we lived to witness miracle after miracle as he survived and triumphed time and time again.

Now, at the age of 13, Baruch is still deaf, has a trachea tube in his throat and eats only through a gastrostomy tube in his stomach, but for a boy that all his doctors thought would never walk or understand or interact, he has proven them more than wrong.

It is now Saturday evening, and today was Baruch's 13th birthday. It is hard for me to say "Bar Mitzvah" because he is not yet ready for the responsibilities of the Torah's commandments, nor do we really know when he will be. Yet, today was a special day. Emotional, but special.

A few months ago, as his 13th birthday loomed closer, my husband and I began to discuss what we should do. At first we thought nothing at all. How could we "celebrate" a "Bar Mitzvah" that wasn't? But then we realized that there was much that we did need to celebrate. We had reached many milestones. Baruch was still alive. He was learning and progressing. He was sharing his special smiles and hugs with all those who met him. He attended synagogue each week and was part of the "*shul* family." But what could we do? We felt uncomfortable making a big affair, yet we could not just ignore the day.

Soon it was March and Passover preparations began. We felt it was time to try to get Baruch more involved in what was going on. We decided to make him a Haggadah (the Passover guide and story), with simple sentences and lots of pictures, so that he could follow the Seder and understand what the whole holiday was about.

My eldest daughter, Chaya Mushka, put it together. We put the pages in a display folder with plastic pockets to protect it from saliva. This became our teaching tool and we went through it with Baruch a number of times before Pesach. Baruch would not let go of his "Haggadah." He sat through the Seder in our home, and for the first time signed the Four Questions. We were very proud.

The big test was the second night. We went to our cousins for the second Seder. There were twenty-two people there. Would Baruch sign again or would he be too shy?

Baruch sat through the entire Seder. When it was his turn, he signed the Four Questions. You could hear a pin drop. There were many children there, and during their turns I must admit that not all the adults kept quiet. But Baruch, who said nothing at all, signed in absolute silence!

For us that was the turning point. We began to think, "If he can accomplish this, why can't he sign the blessings on the Torah in synagogue?" Right after Passover we began planning a "Bar Mitzvah book."

We took pictures of the shul, of the Torah and the *bimah* (where the Torah is read) and of Baruch. We began to think of what the notion of responsibility could mean for him, and we came up with a few ideas: keeping his kippa on his head at all times, the ritual washing of his hands in the morning, not mixing up my milk and meat dishes in his attempt to help clean up, keeping his room clean and not switching lights on and off on Shabbat to name a few. These became the basis of the Bar Mitzvah book. We started with the order of the Bar Mitzvah day: Baruch will go to shul with his family; the *aron kodesh* (the Ark) will be opened, the Torah will be taken out and put on the *bimah*; Baruch will be called up to the Torah, Baruch will sign... And we included the blessings. We sent the book to school as well so that his teachers could practice with him.

We then called the synagogue and explained that we would be sponsoring the Kiddush (meal following Shabbat services) in honor of Baruch's birthday. Our synagogue has an email notification system and we asked that everyone be notified of the occasion since we were not sending out any formal invitations. I also called my cousins who live here in Melbourne to join us in our shul and to stay for the Kiddush. We decided to cater it ourselves. My husband and I made a number of salads, my cousins and friends pitched in too, with gefilte fish, spreads, cakes. We thought it would be a small affair.

Boy were we mistaken! We did not realize the impact Baruch had made on all the people here. Word spread in the general community and people began approaching us to wish us *Mazel Tov* and the informal "invitation list" grew bigger. Our *simcha* (joyous occasion) was not only the shul *simcha* but a community *simcha*. The shul was packed. We were nervous. Baruch can get very silly in a crowd. Would he be able to sign the blessings as he practiced or would he become silly and shy?

Baruch went up to the *bimah* along with his father who was going to translate into English what Baruch was signing, and then recite the actual blessings on the Torah. When Baruch got up there he began shyly, with one hand in his mouth. Signing with one hand is not a very comprehensible language, let me tell you. He slowly gained confidence and he beautifully signed the second blessing after the reading of the Torah. The whole shul erupted in a spontaneous *Mazel Tov* dance. Baruch was put up on his father's shoulders and all the men began dancing in a circle around the reading table.

What can I say? I cried. I think many people did. A bar mitzvah celebration is supposed to be the day when a young boy becomes a "man," a person responsible for his actions. For us, this is not the case. Baruch is still a young boy (he functions at the level of a six year old) and will probably be so for a number of years to come. But that was not what I was thinking at the time and I don't think that is why I cried. I can't really tell you why I cried. I just did. Maybe it was the pent up emotion of all the years. Maybe it was the relief that my son who we were told would die twelve years ago, was standing there at the Torah blessing G-d who had given him life. Maybe it was the outpouring of kindness, support and well wishes from all the people in the shul. Maybe it was because my immediate family was not there to witness this moment. Maybe and maybe not.

Baruch was very excited; he shook everybody's hands and gave spontaneous hugs. The Kiddush continued for a few hours. One by one, family members and friends got up to say a few words. They described how they had been touched by Baruch and by the family. It was very humbling for me as were the comments many people wrote on the web after my previous article about Baruch.

You see, I do not see myself as a "courageous woman" as some have called me. I struggle, I make mistakes. But as a Jew who has learned Chassidut, I forge ahead. I do not think of what could have been but of what I need to do. I am not "brave." I have my down times, I have my cries, I am human. But knowing that I have a G-dly soul, that we all do, gives me strength when I need it. Each of us has challenges in our lives. They are all different, but they are challenges that we struggle through.

People who hear my story say that I have inspired them, but let me tell you that they have all inspired me too. It is one thing to believe that all G-d does is for the good and it is quite another thing to see the good in a revealed way. Of course "good" is a relative thing, and there are many levels of good. But when I see how much Baruch has affected the people around him, when I hear your anecdotes, when I hear that you are more patient, more forgiving, more thankful and more tolerant because of Baruch, then you help me to continue doing what I need to do. You have "recharged my batteries" and for that I thank you all.

May the acts of goodness and kindness spread so that the world at large will be ready to greet [Moshiach](#), when all the mysteries of G-d's ways will finally be revealed to us all.

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The Asian Community and Disability

- A personal view, by Kuli

The Asian community regards disability with such abhorrence that they do not want to demonstrate that it exists. They continually refer to it as a punishment for your previous life. This affects so much of your life activities which normal people can do such as going out, going to university, getting married, cooking, having children, having relationships, having hobbies, interests and working. Disabled people within the Asian community are regarded as less likely to obtain these qualities due to the pressures and unawareness of others.

I proved this wrong.

Being an Asian woman born with cerebral palsy was extremely daunting especially living in an Asian community. I recall my mother saying “When you was born 32 years ago in India without any medical support, you were looked upon as double negative; being a girl and disabled. People said throw “it” in the river, who’ll marry her, she’ll be a burden on you for the rest of your life.” With this restricted mentality and pressures, my mother almost did. It was my father who saved me, and brought me over to England at a very young age.

I went to “Penn Hall Special School” where I was with other children with disabilities. I gained a lot from that school, because they offered us opportunities I would have never had in an ordinary Asian household or school.

I was very timid and shy especially when I was with other people, particularly when visiting people and community celebrations such as weddings, parties and visiting temples. I hated it because people just used

to stare at me, and make me feel unimportant, alienated and an invalid. I was referred to as “handicapped” a word I loathed. Other children teased me, “Why do you walk like that, and talk like that?” I never answered their questions because I didn’t know myself. My parents were very unaware of this, when I mentioned this to them, they said it was my fault and I shouldn’t let it worry me. My younger brothers and sister were able-bodied and never understood how I felt. They too would make fun of me and gang up on me. This led to continual depression and unsettlement.

When I entered mainstream school into which my uncles referred me because they knew I had potential of gaining qualifications; this was quite a shock, as I was on my own in a secondary school (Colton Hills) full of “able-bodies” pushing, forceful, shoving and rough children. I loved this, because I wanted to mingle with others, but I was always afraid that I would be knocked about in the playground, where once a very large person was pushed onto me and almost flattened me. I started to enjoy this school lifestyle although I still had the protection from the school nurse and teachers and a taxi service taking me to and from school. I was very mischievous and explorative, trying all the things that the other children did. Many children started to behave like I had no disability, and the awareness of disability at Colton Hills grew, due to the increasing intake of children with disabilities.

Outside of school, I was trying doing all the things an Asian girl could do, except make the chapatti’s, which I could not manage. I had a passion for writing prose and poetry, which I wrote for pleasure as well as pain. The things I could not express to others I wrote on paper. I gained my GCSE’s and BTEC National. But I was very disappointed that I was not able to attend university, because my parents said I would not be able to manage

alone. Then an opportunity rose to work for Wolverhampton Council, where I work to this day.

I experienced a long and awful time, while searching for a life partner. My parents and I made mistake after mistake. I suffered dreadful heartbreaks and heartache. But in the end I married a lovely man whom my parents had found for me in the first instance, but when I was not ready for commitment. Now I have a home, husband, two lovely boys and lovely people in my life. I thank God for the determination he put in me to fulfil my dreams. I know that some people are not that lucky.

When I see people in my community they are still very stunned and amazed to see that I have done all these things in my life, they don't see me as human, they see me as a living thing who should not have rights or a mind of my own. They say "You must have done something good in your previous life, that is why God is standing by you!"

My conclusion to this is that disability is not one person's problem, it is the whole community's problem. Everyone has a disability, ones that can be seen and ones that can't. It is the visible disability that is the problem in our community. The alienation of disability is in our routes, and this will take many generations to grow out, especially in the Asian community due to the lack of education and awareness

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http://www.1voice.org.uk/HC/personal_view.htm

Exploring Disability Issues in Vietnam

By Sharon Nguyen

I was born and raised in the United States, but I have always wished to visit Vietnam and see the place where my parents and grandparents are from. Because of my experiences growing up as a person with a disability in the Asian-American community, I decided that it was time to go to Vietnam to see if it was as people had described.

Whenever I asked about Vietnam, my family and friends told me that it is not a good country for people with disabilities, and discouraged me from going. They said I would be made fun of and harassed because I have cerebral palsy. Since many Asian cultures believe in reincarnation, many believe that people with disabilities had done something bad in their past lives. Before my trip, my father warned me about the emotions I might feel when encountering other people in Vietnam. This made me a little wary, but I decided I would definitely make the trip anyway.

At the time, I was working at an independent living center in California and doing disability awareness work in the Vietnamese community. I have seen positive results, including an increased acceptance of people with disabilities by the Vietnamese community. When I was selected as a recipient of the Paul G. Hearne/AAPD Leadership Award (see below), it gave me greater confidence to become a stronger leader and promote the acceptance of people's differences and capabilities in my upcoming trip to Vietnam.

Before my journey, I fortunately made contact with several Vietnamese interns who were in the United States to learn more about disability issues and bring ideas back to their country. They helped me to locate new contacts in Vietnam and I made plans to be there on April 17 – National Disability Day. Sadly, my travel plans ended up causing me to miss this special day, and my parents and I arrived in Hanoi on April 18 – the start to a great and unforgettable trip.

I met with about a dozen disability organizations, mostly in Hue. One contained a sewing shop where they made clothes for school children. The people seemed very happy to be employed. At a school for the Deaf and hard of hearing, we discussed the need to continue to work hard to break down barriers. I also went to a school for the blind, where students lived during the week and spent weekends with their families. I visited a physical and occupational therapy center that works with young children with cerebral palsy, and spoke with parents on the importance of starting to train children at an early age to be independent. Before I left Vietnam, I attended a meeting on the Individuals with Disabilities Education Act (IDEA), a U.S. law that addresses standards and expectations for assuring a good education for children with disabilities. People in Vietnam will try to implement similar guidelines.

In terms of accessibility in Vietnam, there is much need for improvement. There are wide, deep ditches along the streets and sidewalks, and very few crosswalks. (Larger cities do have crosswalks.) Vietnam has little law enforcement for cars and motorcycles, so you can picture what it must be like. However, there are ramps for motorcycles on the street corners. Most of the time my parents pushed me in my wheelchair on the street, close to the ditches, because the sidewalks were filled with store owners selling food, clothing and so on. Since most buildings had steps, my parents

would help push my wheelchair up them.

In spite of all of the accessibility issues, I had a great time. In addition to visiting many organizations, I met relatives from both sides of my family. Contrary to the warnings I received about what to expect, the people in Vietnam greeted me with open arms, often coming up to talk to me as if we knew each other. I hope to visit my homeland again to help improve accessibility and build leadership for people with disabilities.

Paul G. Hearne/AAPD Leadership Awards Program

American Association of People with Disabilities (AAPD) established these awards in 1999 in honor of the founder of AAPD. A key disability rights advocate, Hearne was also a successful lawyer and mentor to many other people with disabilities. Much of his life was dedicated to opening doors and removing barriers for people with disabilities.

The award recognizes up to ten emerging leaders with disabilities each year who have a positive impact on the disability community, providing a \$10,000 grant to continue their leadership activities. U.S. residents with any type of disability are eligible to apply. For further information contact:

[American Association of People with Disabilities](#)

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Source: http://www.miusa.org/ncde/stories/nguyen/story_view?month:int=6&year:int=2006

What is CP?

Cerebral palsy (cp) is not a disease or an illness. It is the description of a physical impairment that affects movement. The movement problems vary from barely noticeable to extremely severe. No two people with cp are the same; it is as individual as people themselves.

"Cerebral palsy" includes a variety of conditions. The three main types correspond to injuries to different parts of the brain:

- ✦ People with *spastic cp* find that some muscles become very stiff and weak, especially under effort. This can affect their control of movement.
- ✦ People with *athetoid cp* have some loss of control of their posture, and they tend to make unwanted movements.

People with *ataxic cp* usually have problems with balance. They may also have shaky hand movements and irregular speech.

Cerebral palsy is most commonly the result of failure of a part of the brain to develop, either before birth or in early childhood. This is sometimes because of a blocked blood vessel, complications in labour, extreme prematurity or illness just after birth. Infections during pregnancy, or infancy and early childhood, eg *meningitis* or *encephalitis*, can also cause cp. Occasionally it is due to an inherited disorder; in such cases genetic counselling may be helpful.

It is sometimes possible to identify the cause of cp, but not always.

The main effect of cp is difficulty in movement. Many people with cp are hardly affected, others have problems walking, feeding, talking or using their hands. Some people are unable to sit up without support and need constant enabling.

Sometimes other parts of the brain are also affected, resulting in sight, hearing, perception and learning difficulties. Between a quarter and a third of children and adolescents, and about a tenth of adults, are also affected by epilepsy.

People with cp often have difficulty controlling their movement and facial expressions. This does not necessarily mean that their mental abilities are in any way impaired. Some are of higher than average intelligence, other people with cp have moderate or severe learning difficulties. Most, like most people without cp, are of average intelligence.

There is no cure, but ... correct treatment from an early age can ease the effects of cp. Occasionally children who appear to have cp lose the signs as they get older. Most importantly, having a disability does not mean that someone cannot lead a full and independent life.

Improvements in maternity services and neonatal care have meant that fewer babies develop cp as a result of lack of oxygen (from difficulties at birth) or jaundice, but they have also meant that more babies with very low birth weights survive. These babies are more likely to have cp.

In recent years there has been a slight increase in the proportion of children who have cp; currently about one in every 400 is affected.

Source: <http://www.scope.org.uk/information/cp.shtml>

A second class refuge

Disabled asylum seekers and refugees are an under-represented and unknown group. Rod Hermeston reports on the struggle faced by those entering Britain to escape persecution and sometimes death

They are sometimes portrayed as invading hoards who just want to take British jobs and claim British benefits.

But asylum seekers and refugees frequently have harrowing tales to tell. For them, this country represents a haven from persecution and even death.

Yet many disabled asylum seekers see only the uncaring face of Britain.

Dr Keri Roberts, a research fellow at York University's Social Policy Research Unit, says: "There is no official source you can use to identify who disabled refugees are and how many there are. The data is just not there".

She has made estimates that range between 5,000 and 26,500. And she fears that the lack of information about disabled asylum seekers and refugees is being used as an excuse to avoid providing services.

As part of her ongoing research she has interviewed 39 disabled asylum seekers and has identified some of the problems they face.

The National Asylum Support Service (NASS) has been responsible since 2000 for asylum seekers who can show that they are destitute.

The government claims full account is taken of disabled asylum seekers' needs when they first enter the system.

They are put in emergency accommodation when first arriving in the UK and are then "dispersed" around the country while they await a decision on their future.

Accommodation can be inappropriate. People with mobility impairments are sometimes put in second floor rooms which they have to share with strangers, says Roberts.

But if they turn down a place which NASS deems to be appropriate, support is withdrawn.

This can be a particular problem for some disabled people if they are sent to cities where they don't have friends to provide care, says Roberts.

While local authorities have a duty to carry out community care assessments, many people are not told. When they are told, authorities can simply fob them off, she adds.

Alison Fenney, head of policy at the Refugee Council, says that there is a lack of clarity over who has responsibility for meeting the needs of disabled people.

If authorities decide, for instance, that a person needs to be rehoused, NASS says it will not pay for that. The Home Office argues this situation is unlikely to arise because appropriate housing is already provided.

Fenney says: "I think the best way of doing it is for NASS to contract with local authorities and pay them for housing costs and subsistence costs, while the authority should pay for any additional assistance costs."

Another problem is that unlike refugees who have been given permission to remain in Britain, asylum seekers cannot claim benefits including Disability Living Allowance.

And instead of receiving other benefits, asylum seekers are issued with vouchers to meet their living expenses. These can only be spent in certain shops.

That means that people with mobility problems who cannot apply for a free bus pass may be forced to trust people who they do not know to go out and spend their vouchers, says Roberts.

The Home Office insists that the needs of disabled asylum seekers are taken into account at the outset.

A spokesperson claimed, for instance, that disabled asylum seekers are already placed in clusters of people from their own ethnic backgrounds who can support them. She says: "We work towards placing people together where there is some kind of support network for them."

But Fenney insists the system is not sensitive enough to meet the needs of disabled people. "I just don't think there has been any serious thought given to the needs of people with disabilities," she says.

"It needs much better liaison between NASS and local authorities. If local authorities cannot provide, then they need to consider where the communities are which might support a disabled person."

So what is being done to change the situation?

The government plans to phase out vouchers and to offer board and lodging in a network of accommodation centres. A white paper on this and other issues was due to be published as DN went to press.

Fenney welcomed the plans to scrap the voucher scheme but says that disabled asylum seekers are still not being given enough money.

It seems there is a long way to go before the needs of disabled asylum seekers will be met.

Karzan Amin, 43, had both legs broken during torture before he fled Iraqi Kurdistan.

He was not able to see a doctor until three months after he arrived in Britain. When he was dispersed to Sunderland there were no friends to support him. He also fell foul of the voucher system.

"I could not travel around because I did not have a bus pass and I was supposed to walk around with my crutches to find which supermarkets took vouchers."

He has only been given exceptional leave to stay in the UK. That means he cannot bring his wife and children over. He now lives in London on the third floor of a hotel, with 100 stairs to climb, when as often happens, the lift breaks down.

Falah Mahmood, 25, also comes from Iraqi Kurdistan. He fled and came to Britain in 1999 after his family were poisoned and he was injured by bullets. When he arrived, an Essex GP would not register him or provide an interpreter.

He has exceptional leave to stay and now lives in Ilford renting a shared flat, but his mental health problems make this difficult.

"This article was first published in Disability Now in March 2002. It is Copyright Disability Now. All rights reserved."

Makasib Shamal

“From birth till now I have worked. I have washed my clothes, kept the house, and gone from here to there,” states Makasib Shamal. Makasib was born into a poor family in Al-Kut, Iraq. Her father was blind and her mother chronically ill. At the age of seven months, Makasib had a serious illness, similar to polio. Her family did not have money to send her abroad for the required treatment. By age one, Makasib was left paralyzed from the waist down.

There were few social services for people with disabilities in Iraq, and little compassion. “My family could not afford a wheelchair. I had to crawl, pulling myself with my hands across the floor, to get around,” says Makasib.

She finally received a wheelchair from the government when she was seven, but it broke beyond repair two years later. For the next four years, her mother carried her to school and left her on a bench where she sat all day. Still, she managed to excel in school and was in the top 2% of her class. Finally, the school recognized her achievements and repaired an old wheelchair for her to use.

At the age of 15 her family hit rock bottom. Her father died and her mother was too sick to work. There was no money, not even for food. Makasib was forced to stop school to work as a tailor and help support the family.

For the next decade Makasib only worked. And then the final blow was dealt. Makasib was married-off in an arranged marriage, and became the man’s second wife. “There was no love between us,” recalls Makasib. “He gave a proposal to my family and they forced me to marry him. I had no choice.”

A bad situation quickly turned unbearable: The five sons of the first wife took to regularly beating Makasib. Finally, after two-and-a half years of marriage, she divorced. “The only good thing that came of it all was my son, Mohammed,” she says.

Free from her marriage, she moved home, returned to her tailoring and made a simple but decent life for her son and mother. “I thought that would be the end of my story. That I would spend the rest of my life sewing and alone,” says Makasib. “But then I received a second gift, my son being the first.”

With the fall of Saddam Hussein’s regime, things began to change in Al-Kut, especially for Makasib and other people with disabilities. With funding from USAID’s Community Action Program, Mercy Corps assisted the community in starting the Al-Kut Society for the Welfare of the Disabled. The initiative came from a group of disabled men and women who all felt neglected by the previous regime. The center is actively registering disabled people, advocating for rights for people with disabilities, and creating a forum for discussing of the needs and issues affecting them.

Makasib was one of the first to register with the Society, and immediately joined the effort as a volunteer. Now, every morning she goes to the center to assist in registering the thousands of new members. She says. “Now I have a place to go and help other people who face the same problems as me. I have a greater sense of purpose in my life. Best of all, I know I am not alone anymore.”

Source:

<http://miusa.org/publications/freeresources/mti/chapter6>



What is Polio?

Polio (Poliomyelitis) used to be called Infantile Paralysis. It is an infectious disease caused by one of three viruses. After initial flu like symptoms, the virus can attack the spinal cord, causing muscle paralysis, which can affect any part of the body.

The most serious cases are those involving the breathing muscles; the patient has to be helped to breathe artificially and even then may die. If the virus attacks the nerves supplying the arms and legs they become weak or paralysed. Some people also have back problems. Any of these symptoms can result in permanent disability.

Polio can be prevented by vaccination followed by boosters.

In the late 1950s immunisation against polio was developed. Fortunately, new cases of paralytic polio are now extremely rare in the UK. Indeed, the World Health Organisation <http://www.who.int/> has set its sights on global eradication within the next few years. This is great news but it is important for the world to recognise that the people who survived the epidemics of this century are still alive. In the UK and Eire, following extensive rehabilitation, many have been able to lead fulfilling, independent lives, often having little contact with the medical profession. To achieve this they were often encouraged to make light of their disabilities and lead as "normal" a life as possible. 20-30 years later some of these people are now experiencing new symptoms for which they need to seek help. These are not age related, and may be:

- Lack of strength and endurance, with increased muscle weakness and fatigue;
- Pain in muscles and joints;

- Respiratory difficulties, particularly in those who spent some time in an Iron Lung Ventilator. This may present with some symptoms relating to sleep.

These symptoms may be triggered by a number of conditions, particularly those associated with a period of immobilization. Late effects of polio are now being recognised and investigated. Much can be done to alleviate some of the symptoms and enable the retention of an independent life, albeit with some modification of life-style.

Although slow deterioration is often characteristic of the condition, with proper management it can stabilise or progress only very slowly.

Source: <http://www.britishpolio.org.uk/qanda.shtml>

Pushpa Martin

My name is Pushpa Martin and I am the Chairperson of the Asian Women's Breast Cancer Group.

I was diagnosed with breast cancer in December 2000, whereby I had a mastectomy, followed by chemotherapy and radiotherapy. When I had breast cancer, I desperately wanted to talk to another Asian lady who had undergone the same treatment for Breast Cancer. I wanted to be able to speak to someone in my own language, who could understand my fears, my anxiety, and my worries. Someone who could just hold my hand and say 'don't worry', you will be 'alright'. Unfortunately I had no one apart from my family members, but it wasn't the same.

It was then that I was determined that a group shall be open. I got in touch with Cancer Black Care, and asked if I could become a volunteer and be able to help other women in similar situation to what I had been through.

Cancer Black Care asked me if I could support a lady that was undergoing radiotherapy and she just needed someone to talk to. I was more than grateful to help. I supported ... [this lady] on the telephone, tried to assure her as much as possible. ... [She] also felt the same way as I had that there was no support group and wouldn't it be great if there was one. ... [She] and I initially set up the group from my home. ...

Source: <http://www.awbcg.co.uk/index.html>

Pushpa Martin first got involved with Breast Cancer Care in 2005 through [its] Same Difference research and subsequent campaign. The results of the study highlighted that people from some minority groups are not getting equal access to information about screening and breast awareness. One area of particular concern for Pushpa is the lack of prostheses in a range of different skin colours. When the hospital provided her with a white prosthesis she found it very upsetting. 'I think I had nightmares about that for days, because they gave me this thing.' Pushpa has been a Breast Cancer Care media spokesperson on this issue many times, appearing in national and regional newspapers as well as on live television. As well as researching and campaigning, Pushpa and a friend have founded the Asian Women's Breast Cancer Group [AWBCG] in Harrow, which meets monthly.

Source: http://www.breastcancercare.org.uk/docs/finding_a_voice_new_0.pdf



What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells. Although cells in different parts of the body may look and work differently, most repair and reproduce themselves in the same way. Normally, this division of cells takes place in an orderly and controlled manner but if, for some reason, this process gets out of control the cells will continue to divide, developing into a lump which is called a tumour. Tumours can either be benign or malignant.

In a benign tumour the cells do not spread to other parts of the body and so are not cancerous. If they continue to grow at the original site, they may cause a problem by pressing on the surrounding organs.

A malignant tumour consists of cancer cells, which have the ability to spread around the original site and, if left untreated, may invade and destroy surrounding tissues. Sometimes cells break away from the original (primary) cancer and spread to other organs in the body via the bloodstream or lymphatic system. When these cells reach a new site they may go on dividing and form a new tumour, often referred to as a secondary or a metastasis.

Doctors can tell whether a tumour is benign or malignant by examining a small sample of cells under a microscope. This is called a biopsy.

It is important to realise that cancer is not a single disease with a single cause and a single type of treatment. There are more than 200 different types of cancer, each with its own name and treatment.

It is acknowledged that despite the efforts of central government and cancer agencies, if you are black or from another minority ethnic group you are more likely to die from preventable and treatable cancers than the mainstream UK population.

Source: <http://www.cancerblackcare.org/>

There are substantial differences in the levels and patterns of cancer in different countries and among different ethnic groups. ... in India and Bangladesh the incidence of breast cancer is four times lower than in the UK ...

In the UK we have limited knowledge of cancer incidence and mortality among different ethnic groups because of lack of relevant data on ethnicity. Death certificates record country of birth but not ethnicity. Figures for ethnic minority groups do not include the Irish, the biggest such group in Britain. The figures we have don't tell us who was born here and who came as immigrants, so we know very little about how being born here affects risk.

Overall, cancer death rates in the UK are lower in some groups such as South Asians and Caribbeans, but the most common cancers for all groups are still lung for males and breast for females. But there are significant differences for some less common cancers such as oral cancer. The Scots and the Irish tend to have higher death rates for most common cancers. Indian women tend to be more at risk from cervical cancer, possibly because of lower uptake of screening, whereas Caribbean women are significantly more at risk from colon cancer. ...

... Prostate cancer is three times more frequent in black men than white men in the UK. We knew this was so in the US but a recent study by Cancer Black Care in East London confirmed it is also true here.

The UK situation does not always mirror that in the US - black and white men present at the same stage in the UK, which is not the case in the US.

There are several suggested causes of the difference between incidence in blacks and whites. They include diet, higher levels of testosterone in young black men, high levels of testosterone in pregnant black women (perhaps imprinted on black men at birth) and increased levels of sexually-transmitted diseases (STDs) among black men.

Source: <http://science.cancerresearchuk.org/reps/pdfs/fullrep.pdf>

Fatima

Fatima is currently studying Product Development for the Fashion Industry at the University of Bolton. Having studied and completed a computer course at Bolton Community College, Fatima wanted to continue her studies and progress towards HE. However, due to Fatima's disability (she is partially sighted and has some difficulty with hearing), the classes she attended were not culturally appropriate for her. In fact, some environments made her feel quite uncomfortable, especially when guide dogs were utilised (Fatima is Muslim and in Islam, dogs are considered unclean). The experience left Fatima feeling demoralised and as a result she stayed at home, not pursuing any form of further education.

Encouraging her daughter to achieve her ambitions, Fatima's mother sought the advice of Yasmin Umurji, Fatima's former deputy head teacher, who in turn put the family in contact with an Outreach Worker - Yasmin Hussain - from the University of Bolton.

Through a lot of encouragement and support from her family and Yasmin, Fatima has now been able to embark on a qualification in fashion design at the University. "There have been a number of barriers which I have overcome with support from Yasmin Hussain. She has supported me from the initial stage and is still mentoring my progress."

When it comes to giving advice to a young person considering going to college or university, Fatima enthuses: "Go for it! It is very important and there is a lot of support available."

Source: http://www.aimhigher.ac.uk/practitioner/aimhigher_activities/work_with_wp_target_groups/best_practice_the_bolton_community_engagement_model.cfm



Mother and Daughter Work to Overcome Disability

"My name is Zhang Bingyu. I'm 14 years old, and I am studying in Changzhou International School."

Hearing those clearly pronounced English words, few people would guess they had come from a girl born with a major hearing disability.

Much of the credit for the girl's language skills is due to her mother, Chen Hui, a resident of Nanjing, said the Nanjing-based *Jinling Evening News*.

Chen described the day 13 years ago when a doctor told her that her 11-month-old daughter Bingyu had a major hearing disability as the darkest moment in her life.

She fell into a deep depression, locking herself up in her room and refusing to speak to anyone. She cried constantly, and felt as though her life was utterly hopeless. Her heart ached whenever she thought about the challenges and discrimination her daughter would face because of her disability.

Even today, Chen has trouble holding back her tears when she recalled this nightmarish period.

Chen finally emerged from her depression when a friend who worked in aural rehabilitation reminded her that Bingyu might never be able to speak if she failed to start learning at the age of one.

Chen devoted all her energy to helping Bingyu understand the world through her sense of touch and sight. She labeled the different objects in their home with cards bearing the Chinese characters for those objects. She taught Bingyu to speak by having her touch the objects and then practice pronouncing the words by mimicking the shape of her mother's mouth.

However, after two-and-a-half years of instruction, Bingyu did not react to any sound. Despite her disappointment, Chen firmed her resolve to help her daughter. She knew that learning to speak could be Bingyu's chance for a more hopeful future.

Things changed magically when Bingyu was three-and-a-half years old and suddenly called out for "mum" one night. Chen was too excited to believe what she had heard. She said that night was the happiest one of her life.

Thanks to Chen's unremitting efforts, Bingyu eventually started mimicking the shape of her mother's mouth when speaking and was accepted by a local kindergarten, though she still had some difficulty in communicating with her friends.

In 1999, Bingyu became the first person in Jiangsu Province to receive an artificial cochlea implant, allowing the girl to hear.

However, the joy of that success faded when it became clear that being able to hear interfered with Bingyu's ability to speak.

Mother and daughter had to go back to the very beginning, with Chen introducing Bingyu to the sounds of the words she had learned as a girl.

Every day Chen busied herself creating all kinds of background noise by knocking on the door, turning on the TV and even flushing the toilet repeatedly. She spoke so loudly at home that she seriously injured her vocal cords and had to have two surgeries.

But her efforts paid off.

Bingyu caught up with her schoolmates and even surpassed some of them. Currently a first-grade student at Changzhou International School, she has become a model student, recognized for her ability to speak

English, play piano, paint and use the computer.

In the latter half of 2002 Chen gave up her job as a cosmetics saleswoman and created a hearing rehabilitation center for deaf children.

The center has worked with more than 70 deaf children, among whom more than 20 learned to express themselves freely and were accepted by regular schools.

The media have seized on Chen's story. Their reports have inspired people from across the country whose children have hearing problems. Many people have got in touch with Chen, hoping to discuss her experiences.

(China Daily March 22, 2007)

Source: China.Org.CN website

Some links to other stories or resources

“Fighting for Uganda’s Blind” - an article by Christine Otieno for BBC Africa Live! about Jane Perfect, married for 12 years when her husband threw sulphuric acid in her face and blinded her because she asked for a divorce: Jane is now the director of Ugandan charity, Blind But Able.

Click <http://news.bbc.co.uk/go/pr/fr/-/1/hi/world/africa/3168540.stm> to read the article on the BBC website.

“Liebe Perla - a complex friendship and lost disability history captured on film” - a review of a film made by Hannelore Witkofski, a

woman of short stature, about Perla Ovitz, the last surviving member of the Hungarian Jewish family of dwarfs imprisoned in Auschwitz during the Second World War and experimented on by Dr Josef Mengele. Click

http://www.disabilityworld.org/07-08_01/arts/perla.shtml to read the review on the DisabilityWorld website.

DisabilityWorld - online magazine (e-zine) featuring a wide variety of news reports, international studies and research, new projects, interviews, book and film reviews focussed on the international independent living movement of people with disabilities. Click

<http://www.disabilityworld.org/index.htm> to go to the homepage.

Yesodot - resources, such as welcoming disabled people into your synagogue, from a website for the families of Jewish disabled children and young adults in Greater Boston, USA.

<http://www.yesodot.org/disabilitymonth/checklist.htm>