

INTERNATIONAL DAY OF PERSONS WITH DISABILITIES, 3 December 2014

HOW TO UNDERSTAND AND RESPECT PEOPLE WITH DISABILITIES: SOME 'DOs and DON'Ts'

By Julian Francis

My elder brother, James, who was born in 1943 with a genetic chromosomal abnormality, Down's Syndrome, and who had a severe learning disability, died in 1999 in the U.K. as a result of negligence. He died of bronchial pneumonia because doctors who were treating him did not take the time and trouble to find out exactly what was wrong with him. He had been suffering with diarrhoea and they treated him for that without properly examining him at the residential care home in which he lived. He died because he was unable to communicate with the doctors and carers supposedly trained to look after people with such difficulties. His birthday, which he always celebrated with a lot of fun and laughter among friends, even going to a local pub for a drink, was 3rd December. This date, therefore, has special significance for me, because, in most countries of the world, 3rd December is observed as the International Day of Persons with Disabilities.

It is only right to ask ourselves if we ever take time to understand the problems, the challenges, the feelings and the aspirations of those people who live among us who, as a result of a disability or disabilities, find their lives more difficult to handle than most of us. When we meet people with disabilities, due to our lack of knowledge, we often feel awkward and embarrassed as we do not know how to react, what to do, or what to say. I am writing down some practical advice which may help in the understanding of how people with disabilities feel. I draw on my own personal experience of growing up with a brother with a severe learning disability and later in life having a son with a similar disability. This experience, and knowing many other people with disabilities who have become close friends, has enriched my life and my work.

Having been responsible, with the help of others, in 1990/91 for putting together the first preliminary draft of Bangladesh's National Disability Policy, and having seen how slowly it made progress, I am well aware of how officialdom looks at the problems of the disabled. The rights of the disabled are always at the bottom of most governments' budget plans, and so, I can only stress that much more work has to be done. Having said that, I am very pleased to see that the Government in Bangladesh is taking a closer interest in the difficulties faced by persons with disabilities and that the Disability Welfare Act 2001 has now been amended and strengthened in Parliament through the Disability Rights and Protection Act, 2013. I have worked with many friends in Bangladesh and elsewhere who have disabilities, and all the time I try to focus on the person and not on the disability and hopefully what I write below will help Government Ministers and government officials better understand what they have to do and how to relate to persons with disabilities. The best advice, however, is that if you do not know how to handle your relationship with a person with a disability, ask him or her for advice. I hope these **Do's and Don'ts** will enrich the lives of those who read them and some of the millions of people with disabilities in Bangladesh.

Don't treat a person with one disability as if she/he is disabled in other ways. People tend to talk in simple single syllable words to people who use wheelchairs, they shout at the deaf, and often address a blind person through someone else.

Don't focus on a person's disability, focus on the person.

- ✓ **Do** ask if you can help- and how to help-if it looks as if help might be needed. You may be shy about offering help. The disabled person may also be shy about asking for it. And don't be offended if your help is not needed-persons with disabilities usually like to be as independent as possible. And don't be put off from offering your help at another time.

Don't say "I wouldn't try that if I were you"-a disabled person is likely to be the best judge of what she/he can or cannot do.

Don't show pity and say, "I don't know how you manage; I'd die if I couldn't walk." It is often hurtful and, under the guise of praise, reinforces the sense of being different.

- ✓ **Do** treat children with disabilities as normally as possible-including not allowing them to misbehave. Disabled children need to learn the boundaries of acceptable behaviour, in their own society, just as other children do.
- ✓ **Do** identify yourself straightaway. A blind person can't always place you by a 'hello'. It's hard for her/him to reply warmly, 'hello', if she/he doesn't know who you are. So, give a name and context; "Hello, it's Tasneem. We met last week at Shahana's house."
- ✓ **Do** make a special effort to remember the name of a person who is blind. Beginning with her/his name is the only way of letting him know that you are talking to her/him.

Don't feel shy about saying things like "nice to see you" to a blind person. She/he may even say it back. It's impossible to avoid words connected with seeing-blind people aren't self-conscious about it and needn't be.

Don't grab a blind person's arm unexpectedly. You'll startle her/him. In fact don't hold a blind person's arm at all! Allow her/him to hold yours. She/he is then safely half a step behind you and so is forewarned of what your next move will be by the change in your position.

Don't say "here's a step"-say, "step up" or "step down." It's dangerous as well as embarrassing to be waving your foot in mid-air when the step actually leads down. Also if the step is exceptionally deep or shallow, do mention it.

Don't leave doors half open. Shut them all the way or open them flat against the wall.

Don't exclude a blind person from television. It gives her/him access to a world familiar to her/his sighted friends.

Don't exclude a blind friend from outdoor activities. Ask if she/he would like to shop with you instead of your doing it for her/him.

Don't chase a child away from a person with a learning disability (often, wrongly, referred to as 'mentally retarded') who might approach her/him. It only perpetuates the feeling that there is something to be afraid and ashamed of if she/he reaches out to touch a child, take her/his

hand and turn it into a friendly handshake-deflecting the attention away from the child and on to yourself

Don't be afraid of a person with a learning disability. Very few are violent-and if they are among people, you can assume that they are not violent. Avoidance and rejection are among the most commonly upsetting things to people with learning disabilities.

- ✓ **Do** be honest and keep promises. Don't assume that a person with a learning disability doesn't understand or remember what you've said. As an example, our son Neil, now nearly 40 years old, who has a severe learning disability, has a very good memory and an amazing sense of direction.
- ✓ **Do** take time to listen to someone who is mentally ill-and don't assume that she/he has no knowledge or opinions of value.

Don't express pity for parents of 'retarded' children-their child is just as precious to them as any child is to any parent.

Don't give advice, except to point someone in the direction of professional help if none is being given and some help seems necessary.

- ✓ **Do** remember that any practical help you offer may need to be given for a long period.

Don't tell a person who is mentally ill to "pull themselves together". If they could, they would.

Don't grab hold of a wheelchair without being asked. The occupant can easily be thrown out by an inexpert enthusiast. Remember to warn her/him if you are going to turn the chair round quickly. In fact, it's thoughtful to tell her/him whatever your next move is going to be.

- ✓ **Do** check with the person in the wheelchair if the speed you are pushing her/him at is comfortable. Too fast-it's unsettling. Too slow-it's plain boring.

Don't lift the chair by the armrests-they'll probably come out in your hands. Do remember that the person may find it hard to hear what you are merrily chattering about-and since your voice, coming from behind, may not compete well with traffic noise. Also, from her/his vantage point, she/he may not be able to see what you are pointing to.

- ✓ **Do** chat to a person in a stationary wheelchair with your head on the same level. It's embarrassing always literally to be "looked down upon" and uncomfortable always to be looking up.
- ✓ **Do** ask her/him how to get a wheelchair up or down a flight of stairs-there are often simple mechanisms or techniques which the disabled person will know.
- ✓ **Do** keep your face clearly visible when talking to a deaf person. Face the light. If you stand with your back to the light or window then you may be silhouetted, wiping out the details needed for lip reading. Don't move around-your deaf friend will miss words each time you turn your face.

Do not distort your face exaggeratedly to 'help' a lip-reader. The subtle signs she/he watches out for will be swamped by such contortions. And don't shout-it doesn't help and can distort hearing aids.

- ✓ **Do** bear in mind that someone who is deaf may be nervous of going out in the dark. Already denied one sense, she/he may be uneasy about being deprived of another. Indoors, make sure she/he has easy access to a safe light. And don't forget to take a torch if you go out at night with someone who is deaf-shine it on your face when you speak.

Don't remain silent if you can't make out what a deaf person is trying to say, or if her/his hearing aid is making a whistling noise. Be frank. How else is she/he expected to know?

Don't condescend. A deaf person's voice may sound strange. But there's no need to behave as if he she/he has a learning disability as well.

- ✓ **Do** play music. People who are deaf can "hear" the beat through the vibrations. Deaf teenagers love records and dancing at discos-the louder the music the better.

(The writer has, since the War of Liberation, had a long association with Bangladesh working in many poverty alleviation projects, has contributed to many programmes to improve the lives of people with disabilities)