

## **Services for Deafblind People – *one plus one equals three***

**Drena O'Malley and Michael Anderson, Deafblind Scotland**

### ***A quote from "Orchid of the Bayou" by Catherine Hoffpauir Fischer who has Usher syndrome***

"Like most deaf people vision more than anything else defined my world. It was through vision that I had language and learning, vision that was sharpened by use and the need to survive. I didn't mind deaf. Although deafblindness took away hearing, it was me community – and that community was based on sight. No matter how I tried to look at it, blindness was terrifying. It was right up there with death".

### ***A quote from A S Moller (2003)***

"In a noisy environment when it is difficult to hear, visual cues such as body language and expressions can supplement our understanding. Likewise, when vision is poor, hearing has a major role in the localisation of sounds and the detection of danger...Since vision and hearing interact, deafblindness means that in this instance, one plus one equals three"

People have lost any possibility of compensation for a single sensory loss by losing the second sense.

Deafblind people don't form a single group. According to the Scottish Executive E-dataset, deafblind people may describe themselves as:

- Deaf with a visual problem
- Blind with a hearing problem
- Partially sighted, partially deaf
- Having Usher Syndrome
- Deafblind Dual impaired
  
- Dual impaired
- Dual sensory impaired
- Hard of hearing with sight loss
- Blind and hard of hearing
- A hearing aid user with a sight problem

But deafblind people won't walk up to you in the health centre and say they are deafblind and need help - or that they need it NOW, not in four weeks time, but now. I had an occasion recently with a deafblind person with a blind partner, wanting to make a complaint to NHS and were told it would take weeks. That's not acceptable.

There lies the first problem - it's hard to diagnose deafblindness. People

won't say they are deafblind and demand services. They won't divulge their difficulty. If they keep nodding and pretending they understand, then they can stop pretending they understand what you are saying. There are real difficulties in getting around.

Deafblind Scotland has 700 members nationwide, and there are 2500 people with dual loss registered in the statistics. We know there are far more than that out there, mostly elderly, struggling to achieve a sense of well-being. Far too many form part of the mental health statistics. Most communicate using tactile means, or some adapted personal means of communication and form a disproportionate number of people with mental health problems. In case I forget, and because I'm bolshie, I don't know if Geoff is here but the number the reasons are small is that if I had the choice to travel or stay here for treatment, I would not go away from home for six weeks. I don't leave home for six weeks. Lots of people need the familiarity of their own environment and won't go away unless they are utterly desperate or miserable.

Recent research - Scottish Executive Community Care and Mental Health Services for adults with sensory impairment in Scotland found that there's a notable lack of research evidence exploring the mental health needs of deafblind adults and there is, perhaps, a lack of understanding that deafblindness does not result in the merging of mental health outcomes for visually and hearing the impaired persons. For this group, social isolation is likely to be compounded by not being able to use a second sense to compensate for communication challenges arising from single sensory loss

Much has been written about the mental health needs of hearing impaired adults. Research has found deaf people to be at a higher risk of mental illness than the general population.

Social isolation has been highlighted in the research evidence as a common outcome.

Lewin –Leigh (2000) points out that “deafblind people face enormous difficulties in communication, mobility and in accessing information which is likely to have an impact on their mental health”.

Moller (2003) asserts that “the aim of all treatments of deafblind people is to reduce their isolation.”

There's a lack of Deaf Awareness on the part of health professionals. If this is true for Deaf People it's doubly true for deafblind people. There's no doubt about that. In the Scottish Executive research it said there is no awareness of the management executive letter, but I have brought 100 copies of this, so there's no reason for you not have a copy of that MEL

letter, saying it's a requirement to have assistance in health settings.

Many local authorities reported people accessing mental health services are not high enough to necessitate services at the local authority level. A number of local authorities suggested that it would be appropriate to have dedicated services at a more general level. I think that does not just mean in one area. There's no doubt we need this in Scotland, no matter how it is formed. Is it necessary to have specialist services for Deafblind people? With all the Disability Equality awareness training, and having worked with Deafblind people for so long, the moves forward have been good but there's still far to go. So with goodwill on the part of everyone, surely communication can be facilitated by writing to each other.

I would like to read you a story. A deafblind man, Bert made his thoughts known to me using tactile communication - "I used to work, but people were always laughing behind my back. So I retired. Sometimes the flies in my house get too much for me, they get into my eyes, it gets too much. I don't mind being in the house. It is the flies. The doctor tells me to keep busy. I can't concentrate with flies behind my eyes, I am deaf but I can hear them buzzing. The doctor gives me pills but they make me sleep. I put a wet tea towel over my head to stop them getting in. If the guide/communicator sees the wet tea towel, I am then taken in. The doctors/nurses can't understand my finger spelling. The guide/communicators come in every day but not all day. The council fumigated my house 2 years ago. I don't know why they won't do it again. I am happy to pay for this. Why won't they do it, and get rid of these flies for me?"

I would like to talk to you about a jigsaw; I want you to remember this. Deafblindness is a uniquely disabling condition, So many checking mechanisms we use everyday are not available. Checking to make decisions, this loss can create in the mind of a Deafblind person a jigsaw where the wrong pieces of information get locked together, they are floating pieces of information which have collided and locked and you know how hard it is to separate two pieces of jigsaw, when you can't get information about your environment, when you constantly misunderstand what is happening around you. Often there are devastating consequences at some future stage. Some Deafblind live with flies, some with ghosts, a common one is people in the basement etc. These are not good neighbours for your mental health.

If you are Deafblind getting the information right is difficult, getting the right information is hugely difficult, checking on information again and again and again and again is essential, but the real one is writing the

information you hold in your head whether it is right or wrong is almost impossible, that is why we have said one plus one equals three. By far the biggest problem is less dramatic than Bert's problem with flies that is depression closely followed by anxiety. Michael has come to share with us his experience of depression.

## **A Personal Account by Michael Anderson**

I was born with hearing impairment, in 1974. At the age of 33, I was registered as blind though I had quite good residual vision but was told I would lose my sight within 6-8 years. Then in 1977 I decided to take early retirement. During those few years I went to the rehabilitation centre, where I learned to read Braille and touch-type etc. I had a government based work place. The technology available now was not available then. I think I was psychologically depressed, however, I took early retirement, went out to the countryside with my family and for the first 2 years things were fine, but from 1979-1981 I had deep depression. My doctor put me onto medication and my wife tried to talk to me and help me. Afterwards she said it was a hard period for her. One of the problems was the blindness was setting in quite profoundly, I used to be able to see people's faces up to a point. It became a shadow then nothing at all. In 1986, one evening, I walked out of the house, walking along the road. Half an hour later a car drove up and it was my minister's car. My wife had phoned up our minister and he took me home. He spoke to me for a while but nothing really happened. Then in 1988 one Sunday in January, I again went out for a walk, this time I had a particular place I was going to. I lived in Berwickshire. The police eventually found me after I had walked 8 miles. The GP got in touch. The social worker I found was understanding but the CPN was abrupt. Then I had 3 children, my first 2 were born before I was registered blind. The third one after I came out of a deep depression. In 2004, my late wife died of a rare cancer disorder. I was numbed and stunned for the first year. I did get support from Deafblind Scotland and Falkirk District Council. After about 6 weeks I decided to go back to be involved with the Sensory Centre in Falkirk. Then last year I was involved in a project. Since October last year I have started going downhill again. Fortunately I have a young GP who was very helpful. I then went to counselling but it can only go so far. I think I could say lots more but I will leave it at that.

**Deafblind Scotland wants a mental health service:**

- Where prevention is more important than treatment and/or cure.
- Where staff have received training and are able to recognise dual sensory loss and act appropriately.

- Where staff are able to interact in a meaningful way with deafblind people.
- Where health boards meet their obligation to provide a guide/communicator service for deafblind people in medical settings.
- Where diagnosis of the second loss automatically brings referral for specialist support to the relevant organisations.
- Where the support is put in place before problems develop, especially mental health problems

My experience is there are few happy endings even for those who can access good services. The loss of mental health in Deafblind people can only result, at best, in remission. Having made the journey into poor mental health, few succeed in returning to good mental health. That is why we believe prevention is more important than treatment or cure.