

Transcript narrative 5

This is life today if you have an impairment or a long-term condition. This is not a biased view, it is a view based on interviews with people who have developed, and are living with, impairments. Findings suggest that medical professionals must, first and foremost, listen to the patients. Patients are the experts in their own condition. It is frustrating for those living with chronic conditions, to constantly have to tell and retell their story to professional after professional. Good communication is vital to good service delivery. It is essential that medical professionals have disability equality training. The social model of disability has been around for decades. The model is based on the principle that attitudinal and physical barriers are the disabling factor, for people with impairments. I would go further. I would assert that the disabling factor is the treatment that I and others with impairments have experienced. It is estimated that 90% of people who experience a physical impairment will develop depression. This has traditionally been noted as a consequence of the impairment. My research suggests that it is not the physical impairment which causes the depression, but the treatment people receive. I recently interviewed a young girl. Half way through she said she constantly had suicidal and homicidal thoughts. I was shocked when she told me that she had not told her doctor or therapist, because she feared her daughter would be taken away from her. She opened up to me because I was listening to her and she felt safe. I called the mental health crisis team. She got help. She was not depressed because of her physical condition, but because she had not been given information about support services. Her only support came from an eighteen year old boy she had met on the internet. Her doctor had prescribed anti-depressant after anti-depressant. These had side-effects, one of these being that the tablets could induce suicidal and homicidal thoughts. Another person I interviewed had complained that she had terrible pain in her neck. She constantly visited her doctor. He sent her for physiotherapy, and in the referral had noted that he regarded her pain as being psychosomatic. The physiotherapist said that her pain was similar that of people in the First World War who imagined they were in pain, so they had pain. Her pain worsened and she sought private treatment. An x-ray revealed a tumour in her spine, which had caused a fracture in her neck. She was immediately hospitalized, and operated on. She was told she could have been paralysed. She now lives with limited mobility and constant pain. Living with chronic lung disease is a constant battle, a battle with infection after infection. People with mucus producing lung conditions often need postural drainage and percussion. It used to be the case that domiciliary physiotherapists would assist patients to keep their lungs clear. This reduced infections and hospital admissions. This service was withdrawn, and now people who have conditions such as bronchiectasis have to clear their own chests. It is impossible for people who live alone to do this. They have more infections and their quality of life is diminished. Strategies for the management of long-term conditions must be proactive. They must prevent conditions worsening. Medical staff must not be frightened by patients who know about the management of their own conditions. Information is power. Service delivery should be flexible and people centred. It must also enhance people's life chances. Take the opportunity to learn from those living with chronic conditions. Remember, one in four people can expect to develop a chronic condition or impairment. I was once a you, and you could become a me. Treat people with dignity and respect. We are all unique and this uniqueness should be celebrated. We are not brave, courageous or tragic, we are just people. Living with a long term condition is difficult enough, without having to battle a system which has not geared itself to the true needs of people with impairments. Before you see anyone, do your own A B

C check. Check your Attitude- your attitude towards the 'person' must not have a negative impact on them, or the way others will see them. 'Labels' are for jars, not people. Check your Beliefs-are they stereotypical, or are they in line with social model principles? Focus on the 'ability' in disability, not the 'dis'. Check your Commitment to improving their life chances. Now is your chance to change things. Game Over.