

# **Bolton Data for Inclusion**

The Action Research Centre for Inclusion

(Sponsored by: The Barrow Cadbury Trust)

at

Bolton Institute of Higher Education.

## **Data No 15 :**

*July 1997*

## **Author(s) :**

*Margaret R Lea*

## **Title :**

*Growing up and living with the stigma of epilepsy*

## **Abstract :**

*This essay is written in the first person because it is autobiographical. It is, in parts, from a child's view, growing up and living with the stigma of epilepsy. It details some of the incidents in a 35 year history of discrimination and a life, paradoxically enriched by that discrimination. The part played in labelling by allopathic medicine and the decision to believe that doctors, for all their wisdom and understanding about the human condition, do not know what is best for one individual.*

For further information contact:

Karen Barton ([k.barton@bolton.ac.uk](mailto:k.barton@bolton.ac.uk)), Bolton Institute, Chadwick Street, Bolton, BL2 1JW, England

## *Growing up and living with the stigma of Epilepsy*

When I was twelve years old, I remember sitting in front of the television and watching a war-time film about Army personnel parachuting into occupied territory. I remember watching them falling through the sky, on the screen and suddenly I was falling with them into oblivion. That was the first of many grand mal seizures. My general practitioner sent me to the local hospital where an electro encephalogram (EEG) confirmed the diagnosis of left temporal lobe epilepsy. Epilepsy is caused by electrical stimulation of neurones firing in the brain. Normally, a chemical "wall" holds back the firing mechanisms, in epilepsy, this wall is breached and the subsequent excessive, synchronised activity causes fits or seizures. These fits or seizures are called grand mal. A secondary symptom is petite mal, in which, ones attention is totally lost and it seems as if some time has elapsed since one was last aware of conversation or happenings, (sometimes called absences).

The doctor gave my mother some tablets which I had to take and told me that I would have to take these for the rest of my life. I, at this stage of the game, did not understand how this was to shape my future.

A few weeks later, I called next door but one for my friend Ruth, we had grown up together and we were in the same class at primary and junior school. I knocked on Mrs Smalley's door. When she opened it, I said "is Ruth coming out to play Mrs Smalley?" She replied "She's not playing with you any more you're a lunatic!" Stupidly, I asked "What's a lunatic?" she said "You are! You've got something wrong with your brain and I don't want Ruth catching it!".

This was the first of many times during the course of my life that I realised I was different from the "norm".

*"The term "defectives" was used to describe people with sensory impairments such as blindness, deafness and the lack of speech. After 1903 people with epilepsy and children termed "mentally subnormal" were also added to this category."*

*(Barnes, 1991, p.18)*

I was fortunate or not as the case may be, to pass my 11+ exam and go to grammar school. My attendance during my first year was patchy due to the frequency of grand mal seizures. My second year was horrendous and by my third year, I KNEW that I must be so "thick" and "stupid" because I couldn't follow what I was being taught. Needless to say, going to school was a nightmare. It just

*Growing up and living with the stigma of Epilepsy*

didn't occur to me that taking anti-convulsants along with tranquillisers had a marked effect on my ability to concentrate and disseminate information. I vividly remember an incident during my second year which enhanced my dislike of school and learning in general. My maths teacher was called Mr. Cheshire. On reflection he had a love of pure maths and found the subject easy. Those who didn't, he could not understand.

However, after one pretty hard homework session, a girl called Jennifer who sat in front of me asked if she could copy my homework as she hadn't done hers. I told her that it would probably be wrong, but never the less, she copied it into her book. Our books were taken in for marking and the following day, Mr. Cheshire asked me why I hadn't done my homework myself, but copied it off Jennifer. I told him that I had done my homework. At break, the discussion between myself and Jennifer escalated into a scuffle, I fell against a radiator, banged my head and had a seizure and was taken to hospital. Going back into that classroom was the hardest thing I've ever done in my life. My seizures got worse - there was no way I could have taken my O levels anyway -I believed I wasn't bright enough. So I left school at 15 years of age with no qualifications whatsoever.

*"Institutional discriminations against disabled people is ingrained throughout the present education system. The data shows most of the educational provision for disabled children and students remains basically segregative, is dominated by traditional medically-influenced attitudes and commands a low priority within the education system as a whole."*

*(Barnes, 1991 p. 28)*

My first job was a junior in a ladies hairstylists. My parent thought it a good thing for their daughter to learn a "Profession" and I didn't have the heart to tell them that I was a cleaner and "go for". One of my jobs was to clean and sterilise brushes and combs after use. By this time I wanted to be normal. So I didn't tell the owners that I had epilepsy when I applied for the job. I lasted three months! One of the stylists was rather temperamental, no doubt due to his creative streak.

He picked up a brush one morning that hadn't been cleaned and enraged, threw it at me! Yes, it hit me on the head and I had a seizure and got the sack. The owners said that they couldn't have someone like me working there ... I would frighten the customers away!

### *Growing up and living with the stigma of Epilepsy*

This was when I first encountered the Disablement Resettlement Officer and was handed a "Green Card" to certify that I wasn't normal and therefore my contribution to society was limited, but of course, valued non the less.

Another lasting memory is of when I worked at a large company as a clerk typist. They were "Doing their bit" by employing disabled people. I was asked if I'd take over the secretary's job whilst she was away on sick leave, I agreed and for six months, did her job as well as my own. When she came back, I was moved to the typing room and told to do the audio typing for the representatives. Not qualified or good enough for this job, I was sacked. It all added to the feeling of inferiority.

*"Society is embarrassed and frightened of those people who are "Different", those who have physical disabilities. It's this unease which makes the employment of a disabled person undesirable as their disruptive influence on a team at work can endanger the smooth running and the productivity.."*

*(Graham et. al. 1990 p. 10 Cited in : Barnes. 1991 p. 78)*

*"Although this statement refers specifically to "physical disabilities", other students have noted that employers hold similar attitudes towards the employment of people with non-visible impairments such as mental illness*

*(Dyer, 1990) and epilepsy (IFF Research 1990)  
(Barnes, 1991 p. 78)*

Life went on and the stress of being different accumulated. At 20 years of age I met and married. At 21 I gave birth to my daughter. At least I think I did. The great day dawned and turned into disaster. I had a succession of grand mal fits and was heavily sedated until the final moments of her birth. I was told that it wouldn't be a good idea to have any more children. Shortly after the birth, my husband left for good. We divorced some 2 years later, with my husband claiming in court, that I hadn't told him I was an epileptic... as if such a thing could be hidden.

The next recountable incident took place in the late 1970's. By this time, I had met a wonderful man who had children of his own and our family now numbered three. On a visit to my GP he informed me that the cost of the drugs I was taking was excessive and wanted to change the epanutin to phenytoin sodium. I didn't understand, but he was the doctor and off I duly went, prescription in hand. Some six months later, I woke up one morning to find that I couldn't walk and

that I had spastic movement in my left arm. I couldn't see very well either. My husband called the doctor and I was subsequently hospitalised for two months. I had what was called, by the doctor, an incompatibility with phenytoin sodium. The drug was, at that time, made into tablet form and although each was roughly a certain dose, it could be as much as twice the normal dosage in one tablet. The cost of phenytoin sodium however, was negligible in comparison to other measured dose anti-convulsant. I recovered, but if under any extreme stress, I sometimes find that I have some spastic movement in my left arm.

During the 1980's the dangers of tranquillisers was reported in the media. By this time, the medical profession had, in it's infinite wisdom declared that the electrical activity in my brain required even greater sedation and, for a period of fifteen years, I took Librium, Valium, Pheno-barbitone and epanutin three times a day. I wanted to live. So I decided not to take any more Librium or Valium. I remember my body wanting tablets. The longing to "pop a pill" was so great. So, I bought a tube of smarties and every time I felt I needed a pill, I took one. It worked for me. My GP struck me off his list when I told him. He said that he didn't want to look after someone who thought they knew better than him, he called me a difficult patient. He retired soon after and I was taken on by a younger group practice.

*"Harris used functional assessments of disability based on a threefold distinction between impairment, disability and handicap...This approach remains close to medical classification of disease. It conserves the notion of impairment as abnormality in function, disability as not being able to perform an activity considered normal for a human being, and handicap as the inability to perform a "normal" social role.*

*(Oliver, 1990 Cited in Barnes 1991. p. 24).*

In 1990, I read a book about disease. For the life of me, I can't remember what it is called or it's author. It said that disease occurred when the mind was unhappy and the subsequent disease that it felt was displayed as illness. To a greater degree I realised that this, certainly in my own case, was true, but decided not to do anything about it for the time being. For the next six months, doing as the book suggested, I thought about WHY I was epileptic and how it had shaped my life.

In some respects, I really didn't need it and in others, depended upon it for my identity.

*"In other words, identity is not something "given" but it is bestowed in acts of social recognition. We become that as which we are addressed".*

*(Berger, 1978 p. 117).*

Reading another book, I read of the text above the Oracle at Delphi, which is purported to have read, "Man, Know Thyself". So this woman set about searching for me. There were things I wanted and things I didn't want. One of the things I didn't need any longer was a label. The only way I could get rid of that item after so long was to prove to myself that I did not require a label in the first instance.

*"Since every individual is confronted with essentially the same institutional programme for this life in the society, the total force of the institutional order is brought to bear with more or less equal weight on each individual, producing compelling masivity for the objective reality to be internalised."*

*(Berger & Luckmann, 1996 p. 193)*

In my infinite wisdom and, on telling my husband of the decision and his utter incredulity was that I could be so foolish. I decided not to take any more tablets for my epilepsy. Instead I tried visualising my head wrapped in a blue turban three times a day. The turban was secure and neat, with no pieces sticking out. So in June 1991 I at long last became a non-labelled being. Three months later when I picked up enough courage to talk to my GP about this, he really wasn't pleased.

*"Traditional explanations of disabled peoples individual and collective disadvantage rest upon the assumptions of the "medical model" of disability". This approach maintains that impairment has such a traumatic physical and/or psychological impact upon individuals that they are unable to achieve a reasonable quality of life by their own efforts.*

*(Barnes, 1994, p. ix)*

I suddenly realised that in this game, doctors need people to be ill, or at least believe that they are ill, otherwise they would lose their reason d'etre. In the social games we play, we need others to be colluded. If there were no wars, there would be no reason for people to be brave. If no one committed any crime, there would be no need for policemen. If there were none to learn, there would be no reason for someone to teach. And so it goes on. We all need others to help us play our games.

### *Growing up and living with the stigma of Epilepsy*

I can't tell you it was easy, it wasn't. At times there was someone hammering baking trays inside my skull with a sledgehammer...or at least, that's how it felt. But gradually, with the visualisation, my life came into focus. Who I was became an issue, before this time, others met my epilepsy first and myself second. What I wanted for me and for me to achieve to feel fulfilled also became an issue. By this time, the children had left home. I hadn't worked for some time. My last job was as a self-employed market trader, which I had to give up because of the epilepsy. By 1992, I realised that I could only continue the search for me alone. My GP recommended counselling. This brought it's own realisation. The main one being that I loved my husband very much, but I was no longer in love with him.

That there was no room in the relationship for me to be who I really was. So with his help, I left. I acquired a one bedroom flat and called that my "Womb with a view". I took nothing save a bed-settee and a standard lamp. With the grand sum of £50 in the bank, I began the search to find me.

During 1993, I was depressed and a visit to my GP resulted in a course of Prozac. You would really think that by this stage I would have known better, but no. Two weeks later, whilst shopping with a friend, I had another grand mal seizure. This was a direct result of taking Prozac. I learned that my body cannot now tolerate drugs of any kind. Shortly after this episode, I contracted pneumonia and had to call my GP and ask for a home visit. When he eventually arrived and made a diagnosis, he commented that all of us need doctors at some time and shouldn't alienate them. I haven't seen him since. I try not to go the doctors now unless it's absolutely necessary.

During this period of evaluation, I realised that I did have a mind of my own, opinions and strong ones at that! I knew that I would never knowingly hurt anyone. That basically, I was a good human being, with wants and needs that were not being fulfilled. I wanted to prove to myself that I was educable. Not some thick and stupid dimwit who had no chance. So I decided to read for a degree. It was the hardest task that I could think of. I signed up for a typing and word processing course at a local college. I passed with distinctions. I signed up for an access course and gained entry into Bolton Institute in 1995.

A part time job became available in October 1995 and I became the project worker at an Older peoples venture in the inner city, where I have worked since. I passed my driving test and I no longer think of myself as a little women with a label, rather, just me.

*Growing up and living with the stigma of Epilepsy*

I really do try to listen to myself. If I'm doing something I ask myself, "Is this making me happy? Is it really what I want to do?" If the answer is yes, then fine, if not, I do something else.

I, at first wanted to say that this experience was my choice, that I was aware of choices in my life, but at 12 years of age I had no choice but to let others who "knew me better" decide for me. This, for me, is the worst type of oppression. Society labelled me as a child and then, threw away my right to individuality at a time when I was unable to have a say in the matter.

Yes, latter in my life I can see that accepting that I had no choice but to take a course of action was a choice in itself. This led to my being labelled and excluded. However, I view this entirely positively. If this had not happened, I wouldn't be who I am at this moment in time. I could not begin to understand those who have for some reason been excluded from society. I work with older people. I try to ensure that their needs are met and that ageism or any other "ism" is not applied to them. We are all unique individuals with stories to tell of the obstacles that we have overcome in our lifetime. Every single one of us has suffered from our humanness. It is part of the human condition. Yet from suffering we learn to be individuals.

*During the course of my studies at Bolton Institute I came across the work of Sociologists such as George Simmel and Erving Goffman. George Simmel developed the conception of sociology by applying the distinction of forms and contents to the social world. "The world consists of innumerable contents which are given determinate identity, structure and meaning through the imposition of forms which man has created in the course of his experience."*

*(Levine, 1971, p. xxxii)*

Contents in this particular case are the needs, drives and purposes which lead individuals to interact; whilst forms are the process by which, individuals can combine to form unities. For Simmel, social worlds are created by individuals giving energy to certain forms. For example, trade unions, monasticism, banks, institutes of higher education etc.. They are subjective, and do not really exist except in the energy that we have created them.

Reading Simmel's interpretation of game play in the social world made me realise just how much we play games. How fragile social reality actually is. Through Goffman's work, I realised the intricate strands of social behaviour that hold the social world together and how adept we are at

*Growing up and living with the stigma of Epilepsy*

game play. We have intricate body language by which we signal our intent to others. We also utilise this facility to inform the world of our social identity.

My own observation is that though being disabled, I appear to be fully able. Not only to appreciate the game of disability, and a "self" crying out to be recognised before the label, but to step back and watch other games that are being played around me. Simmel worried that there was no room in urban society for individuality. He need not have worried. It is alive and well as we progress into the second millennium.

***References***

- BARNES, C. (1994) Disabled People in Britain and Discrimination. London. Hurst & Co.
- BERGER, P. (1978) Invitation to Sociology : A Humanistic Perspective. Middlesex. Penguin.
- BERGER, P. & LUCKMANN, T. (1966) The Social Construction of Reality. Middlesex. Penguin.
- DYER, (1990) Cited in : BARNES op. cit. p.78
- GOFFMAN, E. (1963) Behaviour in Public Places
- GRAHAM et al (1990) Cited in : op. cit. p. 78
- IFF RESEARCH (1990) Cited in : op. cit. p. 78
- LEVINE, D.N. (1971) (Ed) George Simmel on Individuality and Social Forms University of Chicago Press.