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# Overcoming the stigma of epilepsy

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### *Abstract*

A prime difficulty facing all people with epilepsy is dealing with the stigma which is associated with it in almost all societies. Stigma arises from the perception of difference from the norm, particularly powerful when that difference is not understood. This arises from the uniquely human need for predictability, resulting from the ability to think abstractly, and thus to surmise the future. A failure of expectation, or the uncertainty caused by an inability to predict, causes insecurity, or a "fear of the unknown", which we try to reduce by rejecting its perceived cause. Stigma can be attached to themselves or their epilepsy by the person with epilepsy, as well as by others about them. Such discomfort is accentuated by perceived inconsistency between the familiar and unfamiliar. Discrimination occurs as a result of stigma, causing people with epilepsy to be preoccupied with epilepsy and expending much psychological energy on disclosure anxiety, vigilance and a consequent uncertainty of identity. This can result in lower self-esteem, self-fulfilling prophecies, self-blame and self-rejection, and ultimately dehumanisation. The most effective means of overcoming stigma is by contact between people with epilepsy and those holding the stigma against them. Such contact must be on an equal status footing, repeated and consistent, require interdependence, be socially approved and enjoyable, contradict the stereotypes held, and be with individuals seen as representative of the out-group as a whole. Hence familiarity, rather than breeding contempt, produces the predictability and consequent comfort and acceptability of the normal.

## INTRODUCTION

This paper examines the phenomenon of stigma from a theoretical viewpoint, explains how it relates to epilepsy, outlines some of the effects of stigma, and suggests ways in which the stigma held against people with epilepsy may be overcome.

People with epilepsy have been stigmatised and discriminated against for centuries, being treated as insane, evil, possessed of evil spirits or contagious.[1] Even in modern societies, they have been institutionalised, segregated and socially rejected. Attitude surveys since 1950 have shown a steady improvement in developed countries, but much improvement is still needed in developing countries

*Stigma* (from *stigmata*, marks, or blemishes) means being negatively regarded because one is different from the norm. All societies develop norms, and those who are perceived as differing from them are stigmatised, or rejected as *abnormal*, and therefore marginalised (i.e., not admitted into normal social interaction). *Discrimination* means unequal treatment based on arbitrary characteristics.[2]

Stigma arises from the perception of difference from the norm, and is particularly powerful when the difference is not understood. This arises from the uniquely human need for predictability, resulting from our ability to think abstractly, and thus to surmise the future. Prediction relies on learning from past experience plus inference from perceived causality. Most people have no experience of epilepsy and do not know what causes it. Thus they feel unable to predict what impact it will have on their future. Inability to predict results in a loss of certainty of control.[3] Consequently a failure of expectation, or the uncertainty caused by an inability to predict, causes insecurity, which we reject, so producing the emotion known as "fear of the unknown".[4] Fear of the unknown arouses negative feelings, which we try to reduce by rejecting its cause - i.e. the people with epilepsy.

Other causes of stigmatisation of the people with epilepsy include (1) Socio-cultural conditioning that normal is beautiful, and beautiful is good; (2) Stress in childhood on the importance of health; (3) Feelings of guilt for being fit and well; (4) Belief that any disability is a punishment for sin; (5) Not knowing how to interact with a people with epilepsy; (6) Repulsion by the

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ugly; (7) Realisation that the body may not be defensible; (8) Perception of the people with epilepsy as a marginal group, outside society; (9) Disability as a reminder of human mortality; (10) Socially inappropriate behaviour by the people with epilepsy, often arising from social isolation; (11) Degree of severity and visibility of the epilepsy; and (12) Demographic and personality factors which influence the likelihood of stigma.[2]

## REACTIONS TO EXPERIENCING STIGMA

Stigma can be attached to themselves or their epilepsy by the people with epilepsy, as well as by others about them. This discomfort is accentuated by a perceived inconsistency between the familiar and unfamiliar. Discrimination occurs as a result of the prejudice and stereotyping arising from stigmatisation, and can cause the people with epilepsy to be preoccupied with their epilepsy, rather than all the other aspects of their lives.[5-7]

Much psychological energy can consequently be expended on anxiety about disclosure (Should I tell? Who should I tell? When should I tell?); vigilance (Who knows? Have I succeeded in concealing it?) and self-identity (Who am I? What worth am I? What do others think of me?).[8]

Stigma and discrimination on the individual can lead to lower self-esteem ("My opinion of myself reflects what I believe others think of me"), self-fulfilling prophecies ("I'm expected to be inferior, so I am not motivated to improve"), self-blame and self-rejection ("I must deserve this: I'm unworthy") and dehumanisation ("Real people are not like this, so I am not a real person").[9]

## OVERCOMING STIGMA

The most important means of reducing the prejudice arising from stigma is by *contact* between people feeling the prejudice and those against whom they feel it.[3] However the contact must be under certain conditions. For one group's prejudice toward another to be reduced, they must experience contact with them which is on an *equal status* footing; is *repeated and consistent;* requires *interdependence;* is *socially approved;* is *enjoyable; contradicts the stereotypes* held; and is with individuals seen as *representative* of the out-group as a whole.[10]

If all these conditions hold true, we will be most likely to re-categorise the group as an in-group, and consequently reduce the stigma we feel against its members. Associations such as Epilepsy New Zealand have worked to do this for half a century.[11,12] How what they do meets the criteria described above is outlined below.

## CONDITIONS OF CONTACT

Contact must be perceived as being between persons of *equal status*. A campaign has therefore been run for many years claiming that most people with epilepsy are within the normal range of employment occupations, physical attractiveness, intelligence, abilities, productivity, sport and recreation talents, energy and socio-economic status.[11]

This campaign was and is run by delivering its message to training institutions, schools, workplaces, sport and recreation events, radio, a website, loans from a video library, TV, newspapers, magazines, doctors' waiting rooms, pharmacists' counters, talks to community organisations, and running an annual National Awareness Week

Contact should involve *interdependence*. Publicity was distributed that people with epilepsy are 1% of the population, they can hold down jobs and contribute to the economy; that anyone could get epilepsy, at any time, so it is therefore worth contributing to costs of research, medical treatment, etc. In addition, self-help groups were established of parents, teenagers, families and others, to encourage inner network acceptance and bonding. The Association assisted to establish the New Zealand Neurological Foundation (NZNF) to fund research into all neurological conditions, including epilepsy. The NZNF now distributes NZ$1.5 million a year. The Association also cooperated with other disability organisations in a national Disabled Persons Assembly

Contact must be *socially approved.* Campaigns were also run to show that it is acceptable to be friendly to a people with epilepsy, as most are normal in intelligence, ability and mental health. It was also stressed that women with epilepsy can bear and rear children, that men and women can work, that most epilepsy is not hereditary and that it can be well controlled by medication. Mainstreaming of children in schools was advocated, and people with epilepsy were encouraged to join clubs, committees, etc. Field Officers were trained to provide support and information to PwE and their families, as well as to inform the public, and a mandatory 2-level nationally recognised qualification was developed for Field Officers. Finally, the Governor-General of New Zealand was invited and agreed to become the active patron of Epilepsy New Zealand

Contact must be perceived as *enjoyable*. Children with epilepsy were encouraged to play sport, go to standard schools and make friends with other children and be in mainstreamed classes. A National Kite Day was established, during which kites were distributed nation-wide to be flown on one day in one place in each town. They were distributed to all interested families, but identified as being in support of those with epilepsy. Social events were run for people with epilepsy and their families, such as bowling, barbecues, picnics, garden parties, and Christmas parties.

The contact must be with persons perceived as *contradicting the stereotypes* held. People with epilepsy who were highly regarded in the community (e.g. Rugby football commentator Keith Quinn), and historically famous people with epilepsy (e.g. Julius Caesar) were publicised. Leaflets were published informing potential employers about successfully employed people with epilepsy. Young people with epilepsy were encouraged to go on to higher education, and the government was lobbied to have people with epilepsy included in Human Rights legislation, the brief of the Health and Disability Commissioner, etc. One branch demonstrated their contribution to the community by fund-raising to buy a building and having it opened by local notables, which provides location and focus for branch activities, and additional office space which they rent out to other local non government health-oriented organizations.

Contact must be with people perceived as being *representative of the whole group*. Publicity was devised showing a variety of people with epilepsy succeeding and living normally, which Field Officers used as they talked to employers and teachers, and visited schools, training colleges, and others. A website was set up which, while it includes chat room, pen pals, teenagers forum, is open to anyone to use.

## RESULTS OF SUCCESSFUL CONTACT

The forms of contact outlined above have resulted in people with epilepsy becoming more capable of competing in society as equals, going out and meeting people more frequently and consistently, joining community groups to work together with others toward community goals (so establishing interdependence), being confident and therefore enjoyable company, contradicting the stereotype of being intellectually impaired and insane, experiencing hope for the future and being accepted as typical members of the population – who happen to have epilepsy.[13]

## CONCLUSIONS

Thus the work of an organisation dedicated to the welfare of people with epilepsy can be planned to meet the criteria for successfully overcoming stigma. Fifty years working in these ways has contributed to the relatively low level of stigma and discrimination currently found in New Zealanders toward members of their community who have epilepsy.[14] That is, familiarity, rather than breeding contempt, produces the comfort and acceptability of the *normal*. Thus the stigma commonly held against people with epilepsy and the resultant discriminatory behaviour toward them can be overcome.

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