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Reducing discrimination against people with epilepsy in New Zealand

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Prejudice "pre-judging" is an unfavourable attitude toward a social group.[1] Thus a person who is prejudiced against a person or group feels negatively about them, believes them to have negative traits and tends to behave negatively toward them all because of the social group to which they are perceived as belonging.[2] Discrimination is unequal treatment based on arbitrary characteristics. Stigma (from *stigmata*: marks or blemishes) is 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; ie: not admitted into normal social interaction.[3]

WHY CHANGE IT?

Effects of prejudice and discrimination on the individual include lower self-esteem, self-fulfilling prophecies, self-blame and self-rejection, and dehumanisation.[4] People with epilepsy (PwE) have been stigmatised and discriminated against for centuries. They have been treated as insane, evil, possessed of evil spirits or contagious.[5] Even in modern societies they have been institutionalised, segregated and socially rejected.[6] Attitude surveys since 1950 have shown a steady improvement.[7,8]

NEW ZEALAND ATTITUDES TO EPILEPSY 2002

A survey of New Zealand attitudes[9, 10] produced positive results. Knowledge was widespread, with 95% of Respondents having heard or read about epilepsy, 73% saying they knew someone with epilepsy, and 67% reporting that they had seen an epileptic seizure. Somewhat less knowledgeable were young people, the less educated, those of lower social economic status, and people of Maori or non-European ethnicity. Attitudes to people with epilepsy were favourable, with only 5% objecting to their child marrying a person who sometimes had seizures. Slightly less favourable were some older people. The question therefore is: *How has prejudice been reduced to such a low level?*

THE IMPORTANCE OF CONTACT

Prejudice can be reduced in a number of ways. An important means is by contact.[11] 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.[12, 13]

If all these conditions hold true then we will be most likely to re-categorise the group as an in-group and reduce our prejudice against its members. That is, familiarity, rather than breeding contempt, produces the comfort and acceptability of the *normal*.

THE WORK OF EPILEPSY NEW ZEALAND

The remainder of this paper outlines ways in which the Epilepsy Association of New Zealand (ENZ) has worked to create conditions of contact between PwE and the general public which optimise prejudice reduction.[14]

Contact must be perceived as being between persons of *equal status*. ENZ therefore pursued a campaign claiming that most people with epilepsy are within the normal range of employment occupations, physical attractiveness, intelligence, abilities, productivity, sport and recreation, talents and energy, and socio-economic status. They also established a nationally recognised qualification in community care for people with epilepsy.[15]

Contact must be *repeated and consistent*. ENZ publicises epilepsy facts nationwide via training institutions, schools, workplaces, sport and recreation events, radio, a website, a video library, TV, newspapers, magazines, brochures in doctors' waiting rooms and pharmacists' counters, and talks to community organizations.[15]

Contact should involve *interdependence*. To promote recognition that New Zealand needs its citizens who have epilepsy ENZ points out that PwE are 1% of the population and can hold down jobs and contribute to the economy. Anyone can get epilepsy at any time so it is therefore worth contributing to the costs of research, medical treatment, etc. Self-help groups of parents, teenagers, families, etc. have been established to encourage inner network acceptance and bonding. ENZ also assisted in establishing the NZ Neurological Foundation to fund research into all neurological conditions. including epilepsy which now distributes NZ$1.25 million a year. Finally ENZ cooperates with other disability organizations in the national Disabled Persons Assembly to promote the recognition that people with epilepsy are national citizens just like anyone else.[15]

Contact must be *socially approved*. ENZ has campaigned to show that it is acceptable to be friendly to a person with epilepsy and that most PwE are normal in intelligence, ability, and mental health. It explains that women can bear and rear children and that both men and women can work. It shows that most epilepsy is not hereditary and is well controlled by medication. It advocates mainstreaming of children in schools and encourages PwE to join clubs, committees, etc. Finally, New Zealand's highest status person, the Governor-General, is the active patron of ENZ.[15]

Contact must be perceived as *enjoyable*. Children with epilepsy are encouraged by ENZ to play sport, go to standard schools and make friends with other children, and be in mainstreamed classes. A national Kite Day was established in which kites were distributed nationwide to be flown on one day in one place in each town. They were distributed to all families but identified as being in support of those with epilepsy. ENZ also runs social events for PwE and their families, such as bowling, barbecues, picnics, garden parties, Christmas parties, etc.[15]

Contact must be with persons perceived as *contradicting the stereotypes held*. National heroes who have epilepsy, such as top sports broadcaster Keith Quinn and popular musician and musical critic Chris Knox have been used in publicity. Similarly, historically famous people with epilepsy from Caesar to Dostoevsky are publicised. Information is sent to employers on successfully employed PwE and the Government lobbied for inclusion as common citizens under Human Rights legislation, the Health and Disability Commissioner Act, etc. At least two ENZ Branches have fund-raised to buy buildings which have been opened by local notables and provide location and focus for Branch activities. Moreover their unused office space is rented out to other local NGOs who thus see PwE as providers rather than beneficiaries.[15]

Contact must be with people perceived as being *representative of the whole group*. To emphasise that most PwE are ordinary people, ENZ Field Officers talk to employers about their employees and to teachers about their pupils, as well as speaking to training institutions and organizations such as the St. John's ambulance and the Red Cross. The ENZ website includes a chat room, pen pals and a teenagers' forum open to anyone to use.[15]

HELPING PEOPLE WITH EPILEPSY TO BE GOOD COMPANIONS

Field Officers are trained to provide support and information to PwE and their families, and must pass a mandatory 2-level, nationally recognised qualification to do so. Their work results 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 (inter-dependence), being confident and therefore enjoyable company, contradicting the stereotype of being intellectually impaired, insane, etc. and being accepted as typical members of the population – who happen to have epilepsy.[16]

CONCLUSION

Hence ENZ facilitates contact between PwE and the general population 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. In other words the work of Epilepsy New Zealand can be seen to be meeting the criteria for successful prejudice reduction. Forty-eight years working in these ways has contributed to the relatively low level of prejudice and discrimination currently found in New Zealanders toward members of their community who have epilepsy.

Thus prejudice against people with epilepsy and the resultant discriminatory behaviour toward them can be reduced.

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