Title: The Development of Marginalisation in Learning Disability Services*

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Introduction

Prejudice exists at all levels of society, finding its basis in over-generalised, learned attitudes towards individuals, who do not conform to what is perceived to be normal by those who hold power in that society (Dworetzky 1991). These attitudes may be directed at any 'deviant' group or individual on the grounds of race, religion, sex, gender-identity and orientation, physical disability, physical disfigurement, behaviour, ethnicity, weight, area of residence, employment status, class, amongst others. Such stereotyping of individuals may further manifest itself in them being treated unequally, solely on account of their membership of that 'deviant' group. Inequality has been defined by the Commission on the Status of People with Disabilities (1996) as: having the same opportunities and status at all levels of society, in the absence of formal and/or informal discrimination against any group or individual. Many disabled individuals who made submissions to that body felt that they "were being either kept at, or pushed to, the margins of society…not being allowed to realise their potential or to participate as fully as they are entitled to in everyday life" (p.5).

That this has been the experience of learning disabled people too, shall be demonstrated within this paper.

This paper suggests that the ongoing marginalisation of learning disabled people has its basis in the negative eugenics theory of the late nineteenth and early twentieth centuries (Dowdney and Skuse 1993, Rafter 1992, Hayman 1990, Llewellyn 1990, Tymchuk 1990, Abramson et al 1988, Behi and Behi 1987, Tymchuk et al 1987, Bass 1963, Hathaway 1947). This shall form the basis for a future examination of the effects of such marginalisation on the developmental potentials of learning disabled people, with reference to a proposed holistic model of the person as a sexual being.

Historical Aspects

In order to understand the reasons for the rapid growth of eugenics in late nineteenth century Britain and the U.S.A, one must first take account of the influence which the industrial and scientific revolution was exerting upon society (Giddens 1997, Worsley 1992). Pre-revolution societies had been based principally on agriculture, although there were some centres of trade and manufacture. These were typically large states, governed by kings or emperors (Giddens 1997), with a simple form of social stratification, dividing aristocratic groups from the rest of the populace. Education too, was principally the realm of the aristocracy, with most of the peasantry being able to neither read nor write (Giddens 1997, Whelan 1995). In the context of pre-industrial society, where the emphasis was on work rather than on education, the problem of learning disability was not a visible one. Multiply handicapped children probably did not even survive pregnancy, and if they did, no health system existed to support their lives (Worsley 1992). Thus, it is likely that those learning disabled people who did survive had, in present terms, mild to moderate degrees of disability, with little physical incapacitation. This supposition is supported by Plater's (1535-1614) classification of mental disease, which identifies learning disability, at that time, solely in terms of mentis imbecilitas (mental weakness).

The Industrial Revolution

The industrial revolution and consequent growth of cities increased the demand for educated and trained individuals (Giddens 1997). In response to this need, modern education developed, thus providing the context for the identification of the intellectual differences between those who could be educated and those who could not (Brandon 1957). This was one factor that highlighted the existence of learning disabled people in industrialised society. A consequence of the apparent ineducability of these people, within industrialised society, was that they formed an

increasingly large portion of the underclass, and so, gravitated towards the poor law institutions (Rafter 1992). This further singled out the learning disabled as a problematic group.

The Scientific Revolution

Developments in scientific knowledge, which took place during the nineteenth century, compounded the problems of the learning disabled. This specifically relates to advances in the understanding of genetics and evolution, and its impact upon societal thought. The new theories proposed by Mendel and Darwin, respectively, challenged the long-held social beliefs that had been supplied by philosophers and theologians (Worsley 1992). Christians had, for example, held to the literal interpretation of mankind's creation, as recounted in the book of Genesis (The Jerusalem Bible 1966). Darwin's suggestion that humans had evolved from animals, questioned the divine nature of humanity, and led to concerted religious opposition (Worsley 1992). This is vividly portrayed in Stanley Kramer's film 'Inherit the Wind' (1960), in which a young teacher, in the State of Georgia, attempts to teach Darwinian evolution in his biology classes, only to be met with imprisonment at the hands of religious fundamentalists.

Whilst most people had hitherto noted that "like begets like, but imperfectly" (Gribben 1993, p.27), it was not until the late 1800s, when the work of Gregor Mendel (1822-1884) was publicised, that the mechanics of genetics became widely known. The main findings of Mendel, recounted by Gribben (1993), in his popular treatise on genetics, are listed below:

1. Each physical character of an organism corresponds to one hereditary factor (gene).
2. In each organism there is a pair of factors which control the appearance of a given characteristic.
3. One factor from each pair is passed on by each parent to each of its offspring.

4. There is an equal probability…of each factor of a pair being transmitted in this way to any particular offspring.

5. Some factors are dominant and others recessive.

<div align="right">Gribben (1993) p.38</div>

When Charles Darwin (1809-1882) published The Origin of Species in 1859, he challenged the widely held views not only of science, but also of society as a whole. His theory of natural selection was based upon three observable facts of nature. He observed that although all species have a high reproductory potential, their populations remain fairly constant from year to year, leading to the conclusion that all creatures face a continual struggle for survival. Noting that there is also inherited variation among individuals of any species, he further concluded that those individuals whose variations best fit them for their environment would be most likely to survive. This is termed the theory of natural selection (Kimball 1974).

Within the context of the theory of natural selection, whereby the survival of the fittest is the norm, it was considered that allowing persons with learning disability (the unfit) to procreate, would lead to a preponderance of learning disabled persons in society, and would ultimately threaten social security (Tredgold 1929 quoted in Brandon 1957, p.711). This was based on the erroneous presumption that the children of learning disabled parents would always themselves be learning disabled (Espe-Scherwindt et al 1993, Tymchuk et al 1987, Reed and Reed 1965, Brandon 1957).

Educational Developments

It has been suggested that the onset of educational policy and the increasing requirement for a trained and educated workforce served to single out the learning disabled, as a part of "the dependent, defective, and delinquent classes" (Henderson 1901 quoted in Rafter 1992, p.17).

Eugenicists, influenced by the new understanding of genetics held that the children of learning disabled parents would always be themselves disabled, due to the belief that "feeblemindedness…behaves as a Mendelian recessive" (Downing 1931 quoted in Brandon 1957, p.711). This sentiment is echoed by Davenport (1911), Fernald (1912) and Neff et al (1915). Allied to this was the positive eugenic stance that the 'fit' should be encouraged to reproduce, and the negative eugenic stance that the 'unfit' should be prevented from doing so (Rafter 1992). Whilst these ideas were clearly based on Darwin's theory of natural selection, they represented the deeply held belief that "all poor, feebleminded women at large become mothers of illegitimate (feebleminded) children soon after reaching the age of puberty" (Neff et al 1915 quoted in Brandon 1957, p.711), and that the multiplication of the 'unfit' threatened humanity with "economic and biological disaster" (Tredgold 1929 quoted in Brandon 1957, p.711).

Institutionalisation

In order to stem this multiplication of the 'unfit', and its perceived threat to society, the eugenicists focused their attention on a specific group: poor, learning disabled women of childbearing age. Prophylactic institutionalisation was commenced, which segregated the learning disabled women from society, as well as removing the possibility of them having a reproductive future. Sexual controls were subsequently imposed on learning disabled men (Rafter 1992). Rafter (1992) argues that the eugenics movement in the United States, under the leadership of Josephine Lowell, also served the purpose of criminalising the fact of being female and learning disabled. This is confirmed by the stated view of the Newark Custodial Asylum that the uncontrolled female body was "immoral, diseased, irrational, mindless" (Rafter 1992, p.25).

The history of institutional care of the learning disabled in Ireland developed in response to the increasing numbers of such people in the poor law workhouses (Commission on Poor Law Reform 1906). Their care was taken on, not by the state, but by religious congregations. It is curious however, that, whilst not formally influenced by the eugenic movement, these institutions bore a stark similarity to those of the eugenicists, both in their segregational policies, as well as in the austerity of their regimens. The reason for this may lie in the commonly held belief of late nineteenth century Irish society, that the root cause of insanity was heredity, this being the most frequent reason for admission to the 'lunatic asylum'. As insanity was, at that time, considered to be synonymous with imbecility, it was managed in a similar way (Robins 1986), with sexuality being seen to be at the centre of the problem. It was observed that women were more susceptible to insanity, due to their being "corporeally weaker and weaker in reasoning power" (Robins 1986, p.111). In order to prevent "the incitement to licentious thoughts and feelings which the presence of females serves to arouse" (Eyre 1948 quoted in Robins 1986, p.135), the institutions enacted sexual segregation and took on the characteristics of total institutions (Goffman 1961), encompassing the total daily experience of their inmates; depriving them of their individuality; and exposing them to coercion and rebuttal. On a broader scale, institutional segregation denied the learning disabled person his civil rights; his potential for development; and his opportunity to partake in everyday life; thus removing him, on every level, to the margins of society.

Whilst the philosophy of normalisation (Wolfsenberger 1972) has pervaded services throughout much of the western world, the movement from institutional care towards a more normalised, community-based system has only developed, in many of the older Irish services, over the past ten to fifteen years. Whereas this is in theory, a positive development, it is the contention of this writer that a general policy of segregation still remains, and that this is supported by sexually

repressive attitudes amongst sections of society and staff towards learning disabled people. With reference to the extensive experience of the writer, it is suggested that this is evidenced by:

1. The continued servicing of many community houses by the institution, for provision of food, maintenance of house and garden

2. Inadequate-use of community based facilities, such as public transport and primary health services

3. The one-sex character of many of these houses

4. Effective social isolation of the groups, due to inadequate planning and poor societal education

5. The custodial nature of the services

6. The perceived need to make learning disabled people more socially acceptable, rather than making society more socially accepting

7. The lack of opportunity for fulfilment of client potentials and for developing extraneous relationships due to social isolation and sexual segregation

Much has been written in the professional literature regarding the attitudes of staff towards the sexuality of learning disabled people (Rose & Holmes 1991, Behi & Edwards-Behi 1987, Craft 1985, Lundström-Roche 1982, Mitchell et al 1978). The negative attitudes encountered by this writer, when questioning colleagues in the multidisciplinary team, regarding the sexual and, particularly, childbearing rights of the learning disabled is further evidence for this.

The Medical Model

The appropriateness of the medical approach to nursing care has been discussed, at length, within the nursing literature. Whereas some authors have defended its contribution to quality of care, others have argued that, through its Cartesian, reductive character, the medical model has steered nursing away from what has, for many, become the essential, central concept of nursing

- holism. The application of an illness-oriented care model, grounded in bio-physiological knowledge, to the care of persons whose needs lie predominantly, within the psycho-socio-educational realm, is, in this writer's opinion, problematic in the extreme, for it fails to address the holistic reality of those needs. It is curious that this model continues to be the pre-dominant force within learning disabilities nursing, in Ireland today. The continuance of such an approach to care runs contrary to any philosophy of normalisation, for it maintains a client-carer relationship that is based on client subservience and disempowerment, rather than on partnership and empowerment. This further contributes to the marginalisation and de-socialisation of learning disabled persons.

Nurses, as managers of both residential and community based units, and as advocates for clients, must ensure that they promote social inclusion, in terms of equal opportunity and achievement of potentials. This may be achieved through the adoption of an approach to care which is grounded in truly holistic nursing knowledge, and of the principals underpinning the philosophy of normalisation, with proper education and preparation of clients for normalised life.

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