Disability, Chronic Illness, and Distance Education

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DISABILITY, CHRONIC ILLNESS AND DISTANCE EDUCATION (DE)

Distance education may be seen as both enabling and disabling in its application to, and relationship with, people with disability and chronic illness. Cutting edge work suggests that it can provide a suitable route to support the studies of students with disabilities and those with long-term health problems. However it is important that this should be regarded in terms of providing choice to students rather than requiring those who are identified as having impairment/chronic illness to undertake studies at a distance. Unless well designed and evaluated, as with any technology, DE can also become disabling in its impact (Goggin & Newell, 2003; Newell & Walker, 1992).

Defining Disability and Chronic Illness in the context of Models of Disability

Within the Western world some 20% of the population has some degree of disability. Yet there are a wide variety of impairments and diverse ways of understanding disability. Taken together, these have significant implications for curriculum design and pedagogy, as well as research and development of educational technology. Considerable differences in life orientation may be found between those who are born with impairment (and for whom such a condition is "normal") and those who acquire them. Those who have visible disability and those whose conditions are hidden can have markedly different experiences, including whether or not their situation is seen as warranting disability support by institutions.

The UK and US have led a marked shift within the international Disability Studies literature in recent years, from the so-called "medical" model of disability to a "social model" (Albrecht, Seelman & Bury 2001). As Fulcher (1989) observes, medical and charitable discourse still dominates everyday understanding of disability. The *medical model* sees disability as a "personal tragedy" located within a deviant individual, to be overcome by providing aids on an individual basis. On the other hand, those proposing a *social model* argue that it is society that creates disability for those with impairments, and that barriers to participation need to be addressed systemically.

The literature also highlights the importance attached by disabled people[1] to the maintenance of personal control over decision-making relating to their needs (see, for example Hunt, 1996; Finkelstein, 1991).

One example which serves to illustrate the marked differences that can occur even within one broad category of disability is the experience of hearing impaired people. A distinction may be drawn between deaf people (who are usually post-lingually deafened) and Deaf people (who are part of the Deaf community). The Deaf culture consists of people who are born or become deaf, use sign language as their first language and identify themselves as being Deaf. A very real issue is whether education and training (a) requires Deaf people to conform to the dominant approaches to disability as deficit and be educated with English (or other oral language) as the main language or (b) will regard Deaf people as being a socio-linguistic minority, delivering training using the appropriate sign language as the dominant form of language. This is inherently an issue of pedagogy. For example, in some instances a Deaf person may benefit from material delivered via video-conferencing with sign language more than written text, depending upon competence. Nevertheless, there are examples from the literature that highlight equalising advantages of using Computer Mediated Communication (CMC) for people with hearing impair-

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ments. For instance, a deaf tutor used a bulletin board for effective group discussion with students; another was able to take part in a staff development conference on-line on equal terms with his non-hearing impaired colleagues. (Ball, Barber, Buckel, Cooke, Gulc, Mole and Sutherland, 2003)

Berry (1999) highlights the diversity occurring amongst members of another major group, the blind and partially sighted population, in relation to the issue of access to the World Wide Web. Watts (2003), a postgraduate student, provides valuable personal insights into the difficulties she encountered when participating in discussions in a Virtual Learning Environment (VLE) using a screen reader. Richardson (2006) suggests that students with print disabilities (including those with visual impairments, dyslexia and motor difficulties) are more likely to adopt a surface approach to learning when frustrated by disabilities that hinder the appropriate use of text-based resources. Craven (2003) suggests that expertise with assistive technology is an important factor for the successful use of a VLE for people with visual impairments. She concludes that a greater emphasis on training will be necessary for the most effective use to be made of the technology.

Debenham (2001) identifies differences between the needs of those with disabilities that are stable (or have stabilised) and those with long-term health problems. Her research explores the experience of distance learners with chronic illnesses in tertiary education, terming these "long-term health problems". In particular the impact of such conditions can be variable, and because they are often hidden, they may not be well understood in terms of "disability," with its stereotypes such as the wheelchair. A further illustration of this is provided by Roulstone (1994) who wryly describes his own experience of disability in terms of being regarded as "a fit person fallen from grace" rather than finding an acceptance of his limitations and ways he needs to work in the light of his condition.

Anti-Discrimination Law

In most Western countries there is specific legislation prohibiting discrimination on the grounds of disability. Such legislation provides exemptions for unreasonable hardship imposed by complying with its provisions, as well as specific exemptions. In countries such as the USA there have also been moves to revise the broad protections offered by such law, reclaiming narrow and stereotypical definitions of, and approaches to, disability (Johnson, 2003). The United Nations Convention on the Rights of Disabled People that came into force in May 2008 marks an important international milestone in this area. In particular, Article 24 requires states to ensure equal access for disabled learners within their educational systems (International Convention on the Rights of Disabled People, 2008). While people with long-term health conditions may be covered by provisions of such anti-discrimination legislation, they may not be aware of their rights or identify as having disability. Indeed, many learners with functional impairment may choose not to reveal their disabilities to institutions.

Studying at a Distance

There are particular advantages associated with studying via distance, flexible and open learning. These include overcoming the inability to attend (or difficulty in attending) traditional educational establishments and the flexibility of study hours, which permit the individual to work when feeling freshest. The latter addresses problems encountered with severe fatigue and pain that can fluctuate from day to day.

Disadvantages can include (a) a lack of social engagement, (b) capital and running costs, and (c) the use of distance education to avoid the issue of making campuses accessible. In the first case, access to a VLE of a distance learning institution can provide one possible way to address isolation for those studying at a distance (Debenham, 2001, 2002; Jennison, 1997; Newland, Pavey and Boyd, 2005). In the second case, capital and running costs can present a formidable barrier to participation for those on a low income as a result of their disability (for further discussion in this area see also Moisey & Moore, 2002; Ommerborn, 1998; Paist, 1995).

Accordingly a very real issue is whether distance education (particularly via Computer Mediated Communication) promotes autonomy? Certainly, there a danger that it might it re-enforce control on decision making on "special needs" by professionals (the old medical model). Yet at its best educational options available to learners with disability/long-term health needs are enhanced (Debenham, 2001; 2002; Newell & Walker, 1991; Walker, 1989, 1994).

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