

Disability, Chronic Illness and Distance Education

Christopher Newell

University of Tasmania, Australia

Margaret Debenham

Consultant, UK

INTRODUCTION

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 U.S. disability studies literature highlights a marked shift 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, and that barriers to participation need to be addressed systemically.

The literature also highlights the importance attached by disabled people¹ to the maintenance of personal control over decision making relating to their needs (e.g., Hunt, 1966; Finkelstein, 1991).

One example that 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) require 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 (Padden & Humphries, 1988). This is inherently an issue of pedagogy. For example, in some instances a Deaf person may benefit from material delivered via videoconferencing with sign language more than written text, depending upon competence. However, in a comparative study of deaf and non-disabled students

undertaken in a distance learning environment, Richardson (2001) concludes that, in terms of both their persistence and performance, students with a hearing loss are similar to students with no reported disability. Berry (1999) also highlights the diversity occurring amongst members of the blind and partially sighted population in relation to the issue of access to the World Wide Web.

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 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 such legislation, as well as specific exemptions. In countries such as the U.S., 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). 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 estab-

lishments 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 “virtual campus” environment of a distance learning institution can provide one possible way to address isolation for those studying at a distance (Debenham, 2001; Jennison, 1997). 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 is a danger that it might reinforce 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; Newell & Walker, 1991; Walker, 1989, 1994).

Methods of Course Delivery: Multimedia

Traditionally distance education utilised print media as its dominant form of presentation. From the 1970s onward this was variously supplemented, in particular with audiotapes, videotapes, and TV in an effort to present material in as approachable a form as possible. Such an approach recognises that learners absorb, process, and operate in different ways. In addition, a variety of institutions around the world have sought to supplement packaged material with face-to-face opportunities, especially in terms of “on-campus schools” geared to the needs of distance learners. While DE has been operational for some time, it is only comparatively recently that issues of disability have been more formally considered in the mainstream literature.

With the growth of the Internet in recent years, the emphasis has shifted to e-mail, Web access (library, course materials, and other resources),

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