

EXPERIENCE AND CONSCIOUSNESS

Notes for Psychology of Disability Talk
Liverpool Housing Authority

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1. Introduction

This is not a paper about the '*psychology of disability*' but rather why there seems to be *no* psychology of disability. It seems to me that an understanding of the psychology of disability must start from the principle that '*we make sense of our world according to the way we experience it*'. If disabled people are denied access to normal social activities we will not only have different experiences to that of our able-bodied peers but we will interpret the world differently; we will see it, think about it, have feelings about it and talk about it differently. The question is, however, '*from what stand-point should this psychological experience be interpreted?*'

2. The Psychology of Disability, I

(a) The service providers experience of disability

Until recently ideas about the psychology of disability have been exclusively created by non-disabled people and almost always in rehabilitation or medical settings. Generally, these interpreters of the psychology of disability have been able-bodied practitioners (doctors or therapists) who work with disabled adults or, very often, disabled children and their able-bodied parents.

But what is the experience of disability that these 'psychologists' try to interpret?

For most workers, therapists, or psychologists, disability is something that they experience (if I can put it this way) when they walk into a hospital (rehabilitation) ward and stand next to a bed, or enter a physiotherapy or occupational therapy room, and turn their attention onto the problems presented by a 'patient'. Alternatively they might be sitting at their work desks and there is a knock on the door. A disabled person, or parent with a disabled child, comes into the room and a set of problems are presented.

In this experience of disability the problem only appears when the disabled person appears. The worker, therapist, or psychologist, naturally associates the problem with the person because this is the way it is experienced. The workers starts to ask the patient questions which are concerned with the problems that the disabled person may have with dressing, walking, eating, etc. They may substitute observation for questioning but the focus of attention of the professional remains on what the person cannot do, or is having difficulty in doing. The attention is not on '*a functioning disabled person*' living in their own home, at work, or school but, on the contrary, on '*a non-functioning person*' in a medical setting.

(b) The service providers interpretation of disabled peoples experience of disability

Contemporary ideas about the psychology of disability have developed on the basis of three assumptions - (i) disability means you cannot function, *you* have problems (that is why the disabled person is in the medical setting), (ii) disability is something that the individual has, or possesses, it is part of you (you are a '*person with a disability*' you are defined in medical terms; 'disability', here, means a chronic personal impairment) and that is why personal caring services are needed, and (iii) the psychological reactions of the individual are all interpreted in terms of reactions to personal dysfunction.

(c) The psychology of disability is the psychology of how service providers react to physical impairment

Since disability is experienced by the worker fundamentally as a negative personal attribute of a patient, or someone in need of *help* (remember *that* is why practitioners are employed by the health or welfare services) any construction of a '*psychology of disability*' in this situation is in fact not a '*psychology of disability*' but a '*psychopathology of disability*'. Current ideas about the psychology of disability are constructs which arise out of the relationship between a worker concerned with alleviating problems suffered by a patient and the inability of the patient to solve these problems unaided (for example, physiotherapists who only see physically 'deformed' children needing treatment can start to believe that all disabled children need treatment).

Under these circumstances psychological reactions of disabled people are interpreted as reactions to basic pathology. Hence the mythology that spinal injured patients have to go through a mourning process before they can adjust to disability (this view has been thoroughly demolished by Dr Mike Oliver). Similar professional experiences or observations in rehabilitation settings with disabled patients can lead practitioners to interpret most behavior of disabled people in terms of compensation for disability (e.g. Goffman's theory of stigma). Failure to get patients to see their problems in the pre-defined ways of the professional (i.e. in rehabilitation programmes) is often interpreted as failure in the disabled individual (e.g. as lacking in motivation).

The key issue in understanding why experts muddle the psychopathology of disability with a psychology of disability seems to do with a fundamental confusion about the meaning of '*disability*'.

3. Disability as a relationship

(a) The functioning disabled person

Instead of looking at a psychology of disability constructed out of pathological experiences from the sick bay, or rehabilitation unit, let us start with the functioning disabled adult.

Video Cartoon 1 – *Saturday Night Out* (3½ minutes) *

If we ask what sense can the disabled people make of their experiences (in the cartoon) then two components seem to emerge:

(b) Making sense of the physical environment

The physical environment has been constructed out of the experiences, and resultant expectations, of young ambulant males (e.g. not disabled people, women with shopping bags, babies in pushchairs, or older people). The physical environment presents a number of barriers and, to these groups, it is disabling.

(c) Making sense of the social environment

The social customs or social norms are derived from able-bodied life styles. Once disabled people have been excluded from the physical environment then it is easy, and logical, for norms to become standard in the public arena, employment, education, housing, transport, etc., which assume the non-participation of disabled people. And once these norms are

* Video extracts from the Open University training pack K665x 'Disability: changing practice'

accepted as standards in the social environment (e.g. building bye-laws, fire regulations) then disabled people will be excluded by these standards from the physical environment. The social environment presents a number of barriers and, for certain groups, it is disabling.

Disability, then, is the product of social and physical barriers excluding people who have some form of physical or mental impairment from functioning in society. It is under these circumstances that disabled people begin to be treated as special cases, as sets of problems to be assessed and prescriptive solutions to be offered. Classically, this involves assessing the individual and trying to fit that individual into the able-bodied social and physical world with the assistance of 'care' from the professional personal services (health and welfare).

Video Cartoon 2 – *Who Chooses?* (4 minutes) *

But where did these standards come from?

(d) The industrial revolution creating disability

If we accept that a psychology of a group emerges when people in that group make sense of their experiences then we need to ask how pathological experiences became the 'norm' for disabled people. In my view the current meaning of disability has its origins in the development of the industrial revolution which eventually swept all previous social relations aside by bringing large scale manufacture and the market into total dominance over our lives.

It is well to remember that disabled people have not always been isolated from their communities (e.g. contemporary literature provides ample evidence of disabled people in their communities as beggars, vagabonds, etc. This can, of course, still be seen in the third world). In these circumstances, although living standards were often appalling for most disabled people disabled people were, nevertheless, part of the community.

The introduction of machinery, on a large scale, however, meant designing the means of production for an abstract human worker (i.e. for normal people - the hands). Since disabled people deviate from this 'norm' they were progressively sifted out of mainstream life and their communities. Ultimately they were put into care when there was a need to remove beggars off the streets.

It is only when this process had been completed in the twentieth century that a psychology of disability began to be developed. In other words, the psychological theories that are presented to us now are built upon the 'precondition' of segregation.

4. The psychology of disability, II

If the theory that disability was created by the industrial revolution, and the view that the current psychology of disability is based upon existing conditions of segregation, is correct then, we must ask, what has changed to make us question these established ideas about the psychology of disability (such as the need to help disabled people adjust and compensate for disability)?

To me, it seems that, like the industrial revolution, a new electronic revolution is taking place and this is opening up the productive processes to participation by non-standard people (i.e. new technology is making all work potentially accessible to disabled people).

However, the latest Office of Population Census and Statistics surveys shows that, whatever the potential for disabled people to fully participate in society, disabled people have only achieved very poor rates in employment (attainment of suitable housing, schooling, etc). This, perhaps, suggests that we are in a transitional stage in the development of a new social status for disabled people. In these conditions we can expect traditional ideas about the

psychology of disability to survive for some time alongside the new emergent concepts. In other words, we are living at a time when a new psychology of disability is emerging. This will be based upon an understanding of disabled people as 'functioning' human beings and will move away from the whole notion of disability meaning 'functional limitations'.

It is not possible to say what such a psychology might be but as disabled people create a more vigorous image of themselves, as they develop a 'disability culture' and provide new ideas about the services they want and need they will also find the need to encourage a new approach towards the psychology of disablement.

We can be sure, however, that assessing 'functional limitations' as a way of planning services (e.g. the theory behind the latest OPCS surveys) or as a way of providing services (as occupational therapists are trained to do) will not survive. This negative approach towards disability is simply inadequate for the changing circumstances which encourage disabled people to take an active role in their own communities.

Thus, as far as housing for disabled people is concerned I believe that this will have to be demedicalised by ensuring that community based 'aids and adaptations officers' are trained from a more appropriate knowledge base - that is, schools of architecture or engineering - and I look forward to these institutions taking up the challenge by providing training courses for a new professional worker (i.e. a kind of 'assistant architectural officer') concerned with assisting disabled people live in their own homes in the community.

When this new professional approach is combined with disability related services making a structural move from 'Health and Welfare' to the 'Department of the Environment' then we will have truly seen the beginning of a new approach towards disability. This will finally clear the last experiential barriers which inhibits the emergence of a wholesome psychology of disability.