

## POINT OF VIEW

### Normalization: The Impossible Dream?

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Normalization of the mentally handicapped has all to do with rights and benefits (Nirje, 1969). The basic problem with human rights is that humans are involved, those who accord them, those who should receive them. To say that the mentally handicapped are entitled to all the rights and benefits enjoyed by the citizens of a democratic society is noble, lofty and altruistic. The right to freedom of speech, the right to freedom of movement, the right to receive education, the right to worship one's own God, all in the context of just and fair laws, have an overwhelming philosophical and moral appeal. How do these and other rights apply to John sitting over there by the window? He is profoundly handicapped and blind, and unless restrained, gouges at his eyes. If prevented from hitting his eyes he strikes at his groin. Since it is "unnatural" to gouge at one's eyes (so unnatural that one wouldn't think of passing a law to prevent it), we apply restraint. If treatment by means of, say, behaviour modification, fails, mechanical restraint may have to be maintained. So, in the interest of humanity, normalization etc. we have to severely curtail one of the few freedoms John presumably appreciates, — freedom of movement. Other groups of people (e.g. criminals) may have to be restrained in different ways in order, for example, to prevent them causing injury to others. The crucial difference between the two examples is that, almost by definition, John does not "appreciate" the consequences of the "unnatural" habit of eye-gouging, whereas the criminal, being of normal or near normal intelligence, does appreciate the consequences of his actions. Put more boldly, John doesn't know what he is doing whereas the criminal supposedly does.

Eye-gouging and other forms of self-injury are so "unnatural" and distressing to witness, they are, again by definition, remote from so-called normal behaviour. The fact that John is profoundly handicapped also presumably means that the rights we have mentioned (freedom of speech etc.) simply have no relevance to his condition. If this is so, the principles we have enunciated lose their universality and thereby much of their effectiveness and appeal.

The difficulties inherent in Nirje's (1969) declaration became evident to workers in mental handicap fairly quickly. Wolfensberger's (1970) variation on the theme suggested that handicapped persons should be exposed to experiences that encourage normalized behaviour. An oft-cited example of this would be the transfer of residents in institutions to the more "normalizing" environment of a community residence. Note that the participle implies that the environment of itself plays an important part. The implication is that, in the community residence, the mentally handicapped adults will do what other normal people do — go to work, enjoy leisure activities and so on. But this, too, is a generalization that is difficult to put into practice. The handicapped individuals may go to an Adult Day Centre and that is probably a more than acceptable parallel with the "normal" person who goes to work. However, it is in the sphere of leisure activities that problems occur. Mr. Smith next door in the community may choose to develop a vegetable garden because he derives satisfaction from it. On the other hand, Mr. Jones,

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two doors down may spend his evening watching television and drinking beer — that's his method of deriving satisfaction. Both sets of activities are indulged in by choice. What if our handicapped residents **choose** to watch TV until the stations close down, **choose** to rock in the bay window, **choose** not to go out.

Professionals soon became aware of this problem too and further modified the concept of normalization by saying that, developmentally handicapped individuals go through the same stages as normal children and therefore account has to be taken of this. If the "normal" toddler goes through a phase of head-banging in his cot and if John (see above) seems to be stuck at this stage permanently, then we have to treat him as we would the toddler. We make the choices, we make the decisions. Hence Nirje's propositions are further modified and diluted.

What of the moderately handicapped, teenage female. She wants a "boy-friend", wants to have a baby. We either can deny her the opportunity to have sexual intercourse or we can have her fitted with a contraceptive. Either way, we are still denying her the freedom of choice, on the grounds that she is a child in a woman's body who does not know how to cope with the problems of child-bearing and child rearing.

What of the mentally handicapped young man of IQ 50 who, for no apparent reason, violently attacks his fellow residents in a hostel. In extreme cases he may have to be secluded in a hospital ward. Professionals, aware of this possibility, introduced another angle to the "normalization" movement, that of "least restrictiveness". In other words, the minimum amount of restriction should be applied commensurate with the difficult behaviour.

Now we have normalization principles which, when boiled down, tacitly accept that individuals cannot add a cubit to their stature. Rather they are involved to prevent excesses: the mentally handicapped adult may be going through the "normal" ten year old stage and must therefore have choices made for them; although physically fully developed and quite capable, physically, of enjoying pursuits open to "normal" individuals, he may be prevented from doing so by us, the professionals who "know better". John, the self-mutilator, should, if treatment fails, wear light rather than heavy splints and wear them for short rather than long periods of time, if possible.

If, to continue with John's case, he lives in a community residence and, in addition to striking himself severely, he also screams a good deal, what of normalization principles then? Will neighbours understand the problem? Will they volunteer to do what they can? Or will we, the professionals, be tempted to remove him from the "normalizing" environment to the remoteness of an institution?

In order to buy a car, buy furniture, in short, live a normal life, we have to earn a living. That is "normal". In order to buy a bike or CB radio the "normal" youngster may have to help out in a shop, do a paper round etc. What about the moderately handicapped person in a hostel? What is she entitled to by right, what must she earn? One could argue that it depends on her mental age. It may be agreed that she will have to earn money or tokens to buy a radio in much the same way a 10 year old might have to. Suppose she likes smoking. If we are tempted to argue that, being an adult, she is entitled to smoke if she wants to, then we apply two standards: she is entitled to engage in some adult activities but not others.

In short, the normalization principles, diluted by successive redefinitions, brings us full circle: the mentally handicapped are different, by definition function at below average social and intellectual levels and do not appreciate lofty principles. The difficulty with the concept of normalization is that it is too often used as an incantation: believe in it ardently and all things are possible. In cold fact, normalization serves two useful purposes. First, it is a defence against the abuse and neglect of the handicapped. By stressing that the handicapped are human and are entitled to as many human rights as they appreciate, we help to protect them. Second, and much more positively, the concept of normalization provides the context in which treatment and training programmes **will** enhance their development, will make them more self-reliant and will thereby increase their confidence and their self-esteem.

#### REFERENCES

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