

POINT OF VIEW

Quality of Life and People with a Very Profound Handicap

In my recent work as a clinical psychologist I have come increasingly in contact with people who have a very profound handicap. By this I mean that they have a developmental age, as measured on the Griffiths Developmental Scales (Griffiths 1954), of less than three months. I have found myself wondering what I should be doing for these people. I was unsure whether my basic philosophy of trying to make people with a mental handicap as independent as possible had any relevance for them. This article is therefore an attempt to clarify my own thoughts on this issue and, I hope, to open up the topic for debate.

Most people would agree that what we should be trying to do for this group is to maximise their 'Quality of Life' (QOL). However, there probably would be disagreements about what QOL actually is and what factors are involved in it (cf Landesman 1986). It may, therefore, be helpful to look how QOL has been interpreted in the past in relation to people with a mental handicap and see what relevance this has to people with a very profound handicap.

What is Quality of Life?

Emerson (1985) in a paper reviewing the effect of deinstitutionalization on people with a mental handicap defines QOL as follows:—

“. . . the satisfaction of an individual's values, goals and needs through actualization of their abilities or life style."

He goes on to say that it has been evaluated in two ways. First by looking at social indications such as physical environment, health, education, etc. Secondly through personal satisfaction, happiness or well being.

Mittler (1984) also discusses QOL in relation to handicap. Though he does not give a definition as such, he does argue that an important constituent of QOL is the opportunity for an individual to make choices between perceived alternatives.

Although these two papers give us a broad idea of how to improve QOL for people with a mental handicap, they do not give us specific details. It is therefore necessary to look at two more areas of the literature. These are, first at the scales that have been developed to assess the environment of people with a mental handicap and secondly at the various variables researchers have used to see whether there has been a positive change in the lives of people with a mental handicap. Although neither of these sources usually refer to QOL directly, I feel it is implicit that what their authors regard as a desirable change must also be regarded as an improvement in QOL.

Scales for Assessing the Environment

Here I am using the term environment in a wide sense, to include not only the physical environment, but also the regime under which the people live. The two scales designed to assess this, that have been most widely referred to in the literature, are PASS (Wolfensberger and Glenn 1975) and The Child Management Scale (King, Raynes and Tizard 1971).

PASS was developed to assess the degree to which an institution or other human service complies with the principles of normalization (cf Wolfensberger 1972), and consequently puts emphasis on whether people are treated as valued members of society. This is done by looking at the service in terms of the following areas: Whether the service allows its clients to integrate into the local community; whether they are treated and encouraged to behave in an age and culturally appropriate way; whether the service is designed to help them develop and whether it treats them as individuals; as well as whether the physical conditions are of a high standard.

The Child Management Scale was developed by King et al (1971) in order to assess the degree to which a facility for the care of children is run as an institution (cf Goffman 1961). The scale looks at four different aspects of institutionalization.

- (i) Rigidity of Routine, i.e. whether the routine is inflexible in not taking account of individual differences and needs in the children and whether it fails to vary from day to day and weekend to weekend.
- (ii) Block Treatment, i.e. whether the children are dealt with in a group rather than individually for such things as toileting.
- (iii) Depersonalization, i.e. whether there is any opportunity for the children to express individuality and have personal possessions.
- (iv) Social Distance Between Children and Staff, i.e. whether the staff and children use different facilities, for example, eating in different places.

Research Indicators of Positive Change

What I am concerned with here are the variables researchers have used when assessing whether a particular environmental change has been for the better. Since there are a large number of papers in the literature on this subject I shall confine myself to drawing attention only to those studies that have looked at people with a severe or profound handicap. The variables that seem to have been used more often are as follows:-

- (i) Improvement in an individual's level of skills or abilities; e.g. Close (1977)
- (ii) Increases in adaptive engagement, i.e. increase in the amount of time people spend doing something purposeful; e.g. Saxby et al (1988)
- (iii) Having a greater range of activities, e.g. O'Neill et al (1985)
- (iv) Increased contact with society, e.g. Firth (1986)
- (v) Decreases in various negative or challenging behaviours such as self-stimulation, self-injury, etc, e.g. Saxby et al (1988)

Components of QOL for people with a mental handicap

From the above it should be possible to draw up a list of variables that determine QOL for people with a mental handicap. This would include both factors about what individuals do, i.e. their behaviour, and about their environment, i.e. the regime and physical conditions they live under. I would suggest that such a list should be as follows:-

1. Factors about the individual's behaviour
 - (a) Level of skills and abilities
 - (b) Level of adaptive engagement
 - (c) Level of negative behaviour

2. Factors about the environment/regime

- (d) The conditions of the physical environment in terms of comfort, food, health care, etc.
- (e) The extent to which the individual is given the opportunity to mix with members of the local community and uses local facilities etc.
- (f) The variability and amount of activities made available.
- (g) The opportunity to make choices.
- (h) The degree to which people are treated as individuals who are valued members of society.

As noted earlier, Emerson (1985) suggests that QOL should be evaluated by looking at both the social indicators and personal satisfaction. Factors d – h in the above list could roughly be regarded as social indicators, however, it is debatable if factors a – c are equivalent to personal satisfaction. The problem is that personal satisfaction, being a subjective measure, has only rarely been used with people who have a mental handicap and then when it has been used it is with people who have relatively mild handicaps. I would therefore suggest that in the absence of a subjective measure one must use objective ones and factors a – c are probably appropriate.

To What Extent are These Factors Relevant to People with Very Profound Handicaps

In order to improve a person's QOL through factors a – c it is necessary to change their behaviour in some way. It is undoubtedly the case that people with very profound handicaps can learn new behaviours (cf Hogg and Sebba 1986; Stainback and Stainback 1983). Also very small gains in skills for someone who is very profoundly handicapped can constitute a relatively large increase in their level of independence. For example, if a child is taught to hold his cup, he could use this skill every day for the rest of his life, or teaching an individual to track a moving object with his eyes would be a major step forward for someone who could not previously do this. Thus for people in this group QOL can and should be improved by teaching new skills, though often careful monitoring of behavioural change and precision training programmes are necessary (cf Hogg and Sebba 1986). However, ~~for some people with both very profound physical and mental handicap one may be limited in what can be taught and consequently to how much QOL can be improved by skill training.~~

A similar argument will apply to trying to improve QOL by increasing a person's level of adaptive engagement, as there must be a minimum level of skill in order to be adaptively engaged. Also it may not be possible to increase QOL by decreasing negative behaviours, as in my experiences people in this group do not generally show self-injurious or other problematic behaviours. It may therefore be that for some people with very profound handicaps even very intensive training programmes can only have small influence on their QOL.

With factor d, which relates to an individual's basic comforts, it is difficult to argue that it has less relevance for people in this group than it does for other groups.

Factors e and f could be interpreted for this group as providing a varied range of experiences and stimulation. I feel this is something that can be done and could be a way of improving QOL. However, it should be borne in mind that people in this group are very likely to have sensory defects and consequently may not be able to take in auditory or visual stimulation. Therefore, if they are to be provided with an effective increased range of stimulation, one must first find out what

stimulation they can perceive. Secondly, one must find out what sort of stimulation they enjoy. Here I would like to refer back to Mittler's (1984) suggestion that being given the opportunity to make choices is an important component of QOL (factor g in the above list). Though it may seem at first glance that people in this group cannot make choices, this may not entirely be the case. It is my experience that people in this group can indicate pleasure or pain. This ability can be used to show which form of stimulation they enjoy, i.e. the ones that produce an expression of pleasure. Thus in a basic way they are exercising some choice. Arranging for people in this group to make these simple choices could also be considered to be giving us an indication of their level of satisfaction or happiness, which as we noted above is considered to be an important subjective measure of QOL.

In my own work with people in this group I have found that careful monitoring of the effect of various sources of stimulation can give very useful information. For example, preferences for a particular colour on a computer monitor, or for a particular type of music can be detected. Also human contact can often be a particular source of pleasure. I have found it useful to produce structured stimulation programmes that can be carried out by staff on a regular basis in order to ensure that residents are provided with appropriate stimulation.

To consider the final factor in the above list. It could be argued that, in objective terms, whether people with a very profound handicap are regarded as valued members of society or not, makes very little difference to them. However, I feel this is probably a very naive view. We know from work in social psychology that how we view people affects how we behave towards them. If, therefore, we, as service providers, view people with a very profound handicap as in some way less valued than people with lesser or no handicaps, then we would feel justified in giving more time to the more valued people and less time to the less valued. People in this group are in need of total care, they will have their own likes and dislikes and need for human contact. Surely this can only be provided in a relationship where the carers value them and when there has been time for a relationship to build up. This point is also taken up by Mittler (1984). He suggests that if a person is seen as a valued member of society in need this could result in more resources being provided that could be used to improve their QOL in an objective way.

Conclusions

It would seem, that in general terms, the factors that determine QOL for people with a very profound handicap are the same ones that determine QOL for people with lesser handicaps. However, there may be a difference in the emphasis placed on the various factors. The scope for improving QOL by changing an individual behaviour may be more limited, consequently rather more emphasis should be placed on providing appropriate forms of stimulation. I would advocate, though, that the same vigor should be given to choosing and applying appropriate stimulation for people in this group as is given to planning programmes to change behaviours. This I feel is important, first, to make sure that regular sessions of appropriate stimulation are given. Secondly, as it is crucial that direct care staff should regard these people as valued, then it is vital that professionals reinforce this by devoting the same time and effort to people with very profound handicaps as they do to other people.

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