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Features

Errol Cocks on Services

John O'Brien Clarifying Normalization

Down's Syndrome: Surgery

Curriculum Guide

A Separate Office of Mental Retardation Services



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Normalization: Resolving Some Contradictions

John O'Brien

The principle of normalization has its critics. Some wonder whether or not it responds to what is real for retarded people especially those labelled "severely or profoundly retarded". These people see three possible contradictions in the principle.

Contradiction 1 Making People Normal

"The principle of normalization says people with handicaps should be socially accepted and valued. But, isn't it devaluing to handicapped people to try to make them normal?"

This criticism rightly points to the fact that people with handicaps are often significantly different from other people. It questions the normalization principle in calling for socially valued outcomes. This criticism is based on two assumptions that conflict with today's realities:

Differences in appearance and behaviour cannot be substantially reduced, the only target of change is the handicapped person's deficiencies.

Two arguments can be raised about these assumptions.

First, recent technical progress reverses a long history of diminishing expectations for developmental progress. Disciplined application of teaching technologies and individualised design of supports for

mobility, posture, communication, and control make it possible for many handicapped people to increase their competence and improve their appearance to a degree that few could have predicted. Developments in applied research make it impossible to predict how many more handicapped people will benefit, and in what ways.

Because the extent to which a person can develop culturally normative or culturally valued skills and appearances cannot be predicted, the normalization principle is stated as a clear and distinct challenge to expectations. It is up to non-handicapped people working in partnership with handicapped people to set the limit on how normative or valued the results of hard and creative work will be. Implementing the principle of normalization leads staff to seek the most valued possible appearances and behaviours for each individual program participant.

Second, the normalization principle is built on the belief that the quality of life for people with handicaps depends as much on the signals our services send about the identity of people with handicaps as on individual changes in behaviour or appearance. This means that the immediate intent is to change the ideas and actions of people who plan, provide, and evaluate services.

Values are shaped by program signals, and technical progress itself depends on changing values. Before much can happen, researchers, teachers, and other developmental specialists have to decide that handicapped people are worthy of

individualised attention. They also have to free themselves of the confusion introduced by the idea of "cure". In the history of services to devalued people, "cure" has had an all or nothing quality to it. One was either "curable" or "incurable". This justifies neglect, or, at best, "humane" custodial care.

Progress began with the realisation that competency has many aspects which can only be defined and developed by seeing past an identity defining label — like "mental retardation" — to the many singular competencies that an individual can develop.

Normalization, then, is *not something that is done to a person. It is a principle for designing and delivering the services a person needs.*

Services designed on the normalization principle are likely to result in increasing competence and social participation for individual handicapped people and in increasing social acceptance for handicapped people as a group.

Contradiction 2 Denying People Special Help

"The principle of normalization says services should use culturally valued means, but if we treat people with handicaps the same as anyone else, they won't be able to develop."

Those who identify this contradiction are concerned with the call for culturally valued means. They point to the undeniable fact that people need a variety of help to develop. But, as defined, the principle of normalization does not deny the need for assistance. It only raises questions for those who design and deliver it.

People who are unable to maintain an upright position on their own need assistance. Some of that assistance may require

applicances and equipment that are anything but typical in appearance. In this situation, establishing an appearance which is as normative as possible assists the development of other valued behaviours. It also requires means that are unusual, such as a positioning chair or a prone board. There is a trade-off between two good things.

People who cannot vocalize need assistance, perhaps in the form of sign or symbol systems, to communicate their intentions. Here, again, there is a trade-off. Those who plan services agree with the handicapped person or his/her family that the accomplishment of being able to communicate intention outweighs the unusualness of the means.

People whose behaviour is unusually disturbing may need assistance in the form of carefully arranged cues and consequences to increase their self-control. This kind of help might be negatively valued by many natural community members. However, if unchanged behaviour would be even more negatively valued, it will make sense to make the trade-off in favour of a less familiar means.

In deciding whether it is worth trading a less valued means for an accomplishment, there are three things to keep in mind.

First, there are a wide range of ways to provide a person with most kinds of assistance.

Program designers should work to select, or create, the least stigmatising, most culturally valued possible means. For instance, behaviour analysts have discovered many alternatives to putting bits of food into the mouths of people who can benefit from systematically engineered consequences.

The rule of thumb should be: start with the most valued or familiar form of assistance that is likely to achieve valued objectives, and only move to a less valued form of assistance if adequate effort does not achieve the objective. Decisions re-

garding an unusual or stigmatizing means ought to involve the person to be served, and/or his representative.

Second, all of us need some assistance in our development, at least from time to time.

As much as possible, assistance should happen at times and places where valued community members are served. As well, as much as possible, the same people should provide assistance to handicapped people as serve valued people.

The need for separate "special" equipment, activities, staff, and facilities should be creatively challenged, and the challenge should be more vigorous the further away from a valued practice we move. That is, it may be that a person needs a special piece of equipment — say a wheelchair. This does not necessarily mean that the person needs special activities, or staff, and it should never mean he/she must use a special facility — though obviously the buildings the person uses must meet the lawful standards of accessibility.

Even a person who needs special equipment, individually designed activities, and uniquely qualified staff, seldom needs a special building. For instance, many multiply handicapped children now attend highly specialised classes in neighbourhood schools.

Third, there is no necessary connection between the right to most opportunities and the achievement of some sort of competency.

For example, all children regardless of the degree of severity of their handicaps are entitled, by U.S.A. federal law, to a free and appropriate public education. This right is not qualified by the attainment of a test score or the ability to toilet oneself.

People who are labelled profoundly handicapped or severely behaviour disordered can live in (adapted) typical apartments in community neighbour-

hoods and develop the skills that they need there. They should not have to earn their way to a more normative setting.

Our society, and our services, tend to underestimate the capacity of people with handicaps to respond to culturally valued situations. Services that have chosen more normative means have found that there are positive responses to the choice of a new setting — perhaps a smaller residence which can honestly be called a person's home.

Thus, the principle of normalization influences a program to select the most valued possible means from the range of available options.

Contradiction 3 Exposing People to Rejection

"There is nothing 'normal' about being handicapped. Most 'normal people' and most 'normal' communities do devalue and reject people with handicaps. It doesn't make sense to base a principle on a wish that other people would be more accepting than they are."

People who identify this contradiction have lots of evidence to back them up.

Within this century, people with intellectual disability have been blamed for "spreading degeneracy", including crime, poverty, dependency, and disease; they have been abandoned, neglected, and abused in segregating institutions; and they have been systematically excluded from almost every opportunity to participate in community life. But this does not necessarily contradict the normalization principle. In fact, it makes a foundation for it. Let's examine this idea in two ways.

First, community acceptance is not an all or nothing affair. Nobody is accepted by everybody, or needs to be.

Everybody does need to be valued and

supported by an interdependent network of people to whom, in turn, that person can lend some support and positive action. Once a person belongs to such a social network the person has a better claim on the resources — at least the tolerance — of the larger community. This provides a lever for change.

If we implement the normalization principle by working to make more and more handicapped people participants in the lives of a variety of community members, they will begin to grow a network of relationships which not only provides support, but also changes the status of the person and the group they represent in the eyes of others. Over the long run, this will reduce the level of devaluation of people with handicaps.

Second, "mental retardation" need not be an all or nothing thing.

Whether a person is accepted and valued only depends on a single fact about the person — such as a very slow rate of learning — if the person has developed no competencies to balance obvious differences, and if the person is treated in ways that signal difference.

The antidote to devaluation has two parts: work hard to identify and remove stigmatizing practices and symbols, and work just as hard to find ways of developing positive characteristics and offering status building experiences and settings.

But is it Practical?

Many people accept the logic of the principle of normalization but see it as impractical. They feel that there are already too many problems in the existing service system, and they believe that it is unreasonable for service providers and evaluators to become concerned with "ideal" conditions.

The principle of normalization is in tension with much of past and current

reality. It questions many common practices. In this sense, it is an important tool for problem definition and priority setting. The tension can be creative; if we choose to make it so.

The principle of normalization is as practical as we are willing to work to make it. It sets a direction. It does not provide a highly detailed road map. It calls for increasing the probability that, over time, handicapped people will more and more live with us as valued neighbours rather than as devalued clients.

"Understanding Normalization" by John O'Brien and Connie Lyle. Atlanta: Responsive Systems, 1984.

Copies available from AAMR national office — \$3 postage included.

The Case for a Separate Office of Mental Retardation — I

Hayden Raysmith

The purpose of this meeting is to establish the case for a separate Office of Mental Retardation in Victoria and to demonstrate to the Victorian Govern-