



NORMALIZATION

By Bengt Nirje

Normalization means...*A normal rhythm of the day.*

You get out of bed in the morning, even if you are profoundly retarded and physically handicapped;

You get dressed, and leave the house for school or work, you don't stay home; in the morning you anticipate events, in the evening you think back on what you have accomplished; the day is not a monotonous 24 hours with every minute endless.

You eat at normal times of the day and in a normal fashion; not just with a spoon, unless you are an infant; not in bed, but at a table; not early in the afternoon for the convenience of the staff.

Normalization means...*A normal rhythm of the week.*

You live in one place, go to work in another, and participate in leisure activities in yet another.

You anticipate leisure activities on weekends, and look forward to getting back to school or work on Monday.

Normalization means...*A normal rhythm of the year.*

A vacation to break routines of the year. Seasonal changes bring with them a variety of types of food, work, cultural events, sports, leisure activities. Just think... We thrive on seasonal changes.

Normalization means...*Normal developmental experiences of the life cycle:*

In childhood, children, but not adults, go to summer camps. In adolescence one is interested in grooming, hairstyles, music, boy friends and girl friends.

In adulthood, life is filled with work and responsibilities.

In old age, one had memories to look back on, and can enjoy the wisdom of experience.

Normalization means...*Having a range of choices, wishes, and desires respected and considered.*

Adults have the freedom to decide where they would like to live, what kind of job they would like to have, and can best perform.

Whether they would prefer to go bowling with a group, instead of staying home to watch television.

Normalization means...*Living in a world made of two sexes.*

Children and adults both develop relationships with members of the opposite sex. Teenagers become interested in having boy friends and girl friends. Adults may fall in love, and decide to marry.

Normalization means...*The right to normal economic standards.*

All of us have basic financial privileges, and responsibilities, are able to take advantage of compensatory economic security means, such as child allowances, old age pensions, and minimum wage regulations.

We should have money to decide how to spend; on personal luxuries, or necessities.

Normalization means...*Living in normal housing*

In a normal neighbourhood. Not in a large facility with 20, 50, or 100 other people because you are retarded, and not isolated from the rest of the community.

Normal locations and normal size homes will give residents better opportunities for successful integration with their communities.



The Normalization Principle and its Human Management Implications.

In R B Kugel & W Wolfensberger (Eds.) Changing Patterns in Residential Services for the Mentally Retarded Chapter 7, pp. 179-195 Washington DC: President's Committee on Mental Retardation. Bengt Nirje (1969).

This short paper is generally accepted as the first definitive statement of the concept of normalisation which had slipped into the world as part of Danish Act No. 192 of 5 June, 1959. This granted devolved powers to the Danish National Service for the Mentally Retarded to provide people with learning disabilities with living conditions as close to those of others in society as possible (Bank-Mikkelsen, 1969). The society's energetic Director, Niels Bank-Mikkelsen, soon came to the attention of Bengt Nirje, the recently appointed Ombudsman of the Swedish Association for Retarded Children. Nirje had worked for the Swedish Red Cross in UNHCR camps for Hungarian refugees in Austria as well as on a project to support parents of children with cerebral palsy before joining the Association. So he had the international credibility and the breadth of experience that enabled him to generalise and to carry the ideas from Denmark to international symposia in Sweden and France and to colleagues in the US through whom he was invited to contribute two papers to the collection to be edited for the President's Committee on Mental Retardation by Robert Kugel and Wolf Wolfensberger. This came out on 10 January 1969 in the dying days of the Johnson presidency (Nirje, 1992).

Key Ideas

A life-style for people with learning difficulties which reflects

- a normal rhythm to the day
- a normal routine to life
- a normal rhythm to the year
- the normal developmental experiences of the life cycle
- having one's choices, wishes and desires taken into consideration and respected
- living in a bisexual world
- normal economic standards
- standards of facilities similar to those others are accustomed to.

Such a lifestyle benefits both people with learning disabilities and their "carers" because both become more in touch with everyday realities.

Content He describes the 'normalization' principle as related to a cluster of ideas, methods, and experiences put into practice with people with learning disabilities that, quoting Niels Bank-Mikkelsen, "let the mentally retarded obtain an existence as close to the normal as possible". But he sees it as a broader principle that can be applied to people with disabilities at all ages and in all situations.

He identifies eight features of the principle:

1. A normal rhythm to the day during which you do similar things at similar times to those being done by others in society but also with the flexibility that other people take for granted in their day to day lives;
2. A normal routine to life, that is to say, living in one place, attending school or going to work in another and participating in leisure activities in yet more places; this also means that people with disabilities have to learn to cope with unexpected, unstructured situations without panicking (Nirje, 1967);
3. A normal rhythm to the year, going on holidays, in some cases abroad, and celebrating birthdays and anniversaries;
4. Experiencing the normal developmental experiences of the life-cycle such as a stimulating environment in the care of a few significant adults during childhood, opportunities for learning about one's own personal abilities and potentialities, for obtaining understanding of oneself, and for building self-confidence in youth, the experience of being accepted, treated, and respected as an adult, including the opportunity to start a life of one's own, as independently as possible and the opportunity to spend one's old age in familiar settings as close as possible to those with which they have been acquainted as adults;
5. Having one's choices, wishes and desires taken into consideration and respected, something which is facilitated by opportunities to express oneself within small groups;
6. Living in a bisexual world where there are both male and female staff and acceptance that wanting to get married and to live together are normal;
7. As normal economic standards as possible, for example, drawing the same benefits as anyone else even where these may have to be topped up and being paid an economic wage for work done;
8. Standards of facilities similar to those others are accustomed to, for example, accommodation no larger than that which other people would occupy as a long-term

residence in locations similar to those of other forms of accommodation.

He stresses that just because different people may benefit to a different extent from the principle is not a reason for denying them life conditions, facilities, and services that follow the normal patterns of society. For one thing, it is a matter of equal rights with other members of society.

Indeed he argues that, because the developmental challenges for someone with a learning disability are so much greater, we should make greater efforts to provide the experiences that will stimulate their growth. Without that, there is little chance of developing a personal identity and a satisfying self-image. Only by experiencing success and taking on responsibilities can someone with a learning disability gain self-esteem and a sense of personal dignity.

A person with a learning disability benefits from reaching a state of accepting himself with realistic self-confidence as an adult and as a responsible person (Cobb, 1967).

Everything in a person's life has a developmental potential. Institutions and public attitudes which stifle this are no use. Isolation and segregation foster ignorance and prejudice, whereas integration and normalisation improve human relationships and understanding.

Normalisation also means that workers have more normal conditions of work which raises their status and self-respect and can lead to increases in efficiency and effectiveness. It also offers parents more normal choices for their children.

The normalisation principle is not a dream but is a reality brought about by hard-headed local authority committees.

He concludes with an Appendix summarising the Swedish experience to date. Swedish law No. 940 dated 15 December 1967 and coming into force on 1 July 1968 provides for a wider range of services and stresses that these services should be given to each person according to his personal needs. People who are on the borderline should be given the services they need.

Services may be provided in residential care or in the community, including day care and home support, and parents should have a choice of the services they will receive.

Adults will be able to live in the community and, where necessary, find work in sheltered workshops. Education, whether in special or normal schools and colleges and including pre-school and vocational education, is to be available to all up to the age of 21 or 23 in some instances.

Each local authority has to make the arrangements for its area, produce a local plan to meet the needs of people with

learning disabilities within the framework of the new law and organise and supervise the provisions in cooperation with existing agencies and facilities.

At the time of writing, a refurbishment programme initiated in 1954 had improved the living conditions in many establishments, often by breaking down large units into smaller ones and, though a few institutions had not yet embarked on such a programme, he foresaw that they would no longer be regarded as an acceptable part of provision for people with disabilities.

He concludes with a few quotations from the Symposium of the International League of Societies for the Mentally Handicapped in Stockholm (1967).

Discussion

The idea of treating people as normal and having normal expectations of them was not new; George Jepson and Katherine Allen had pioneered it with mentally ill people and a small number of people with learning disabilities at The Retreat in York over 150 years earlier (Glover, 1984) but they had done so within an institution which had good links with the local community in which residents were encouraged to participate and which most residents left within two years to return to the community.

What was new about the Danish implementation and Swedish development of the normalisation principle was its continuity and comprehensiveness; this is not just a short term treatment method but a long term approach to dealing with people with learning disabilities which can be applied to almost any excluded group and which will benefit staff as well as families by bringing greater normality to their lives.

The benefits of offering people in residential care as normal an experience as possible was to be demonstrated in English research which had been going on during the Scandinavian developments (King et al., 1971) but having one's choices, wishes and desires taken into consideration and respected was a new idea; after all, from the 1914 Elementary Education (Defective and Epileptic Children) Act until very recently, it had been assumed in the UK that severely disabled children were uneducable and those less severely disabled had to be provided for in special schools. At the time even those without learning disabilities did not have their views taken into account (Page and Clark, 1977).

As for living in a bisexual world, as Wolfensberger (1969) had pointed out in the same collection, two of the commonest perceptions of people with learning disabilities were as sick or as subhuman, the latter having been reinforced in the UK by the adoption of the term 'subnormal' as recently as the 1959 Mental Health Act. The idea that people with learning

disabilities might have sexual relationships was not really to be discussed until later in the decade after the study by Craft and Craft (1979) had been published; but if adults with learning disabilities are to have sexual relationships, it follows that adolescents with learning disabilities will need to receive education in sexual and personal relationships in order to handle sexual relationships as adults.

One of the major difficulties for those wishing to provide normal economic standards for people with learning disabilities has been finding ways of rewarding them which are commensurate with those of people without learning disabilities and yet ensuring that they do not fall into poverty. So far UK governments have side-stepped the problem by providing sheltered workshops for some and leaving the rest on benefits.

Standards of facilities similar to those others are accustomed to did not become mandatory until the 1995 Disability Discrimination Act. Nonetheless, it is worth reminding ourselves that Nirje did not expect that the normalisation principle would lead to everyone with a learning disability being treated or behaving in the same way; rather it would remove the barriers that prevented them from being able to live lives which were as normal as possible for them in their circumstances.

The Nirje–Wolfensberger Controversy

Nirje clashed early on with Wolfensberger, the advocate of normalisation in the US, over the extent to which normalisation should be prescriptive. In an article with Burt Perrin (Perrin and Nirje, 1985) he regretted using the word 'norms' in this paper because, he argued, Wolfensberger had misinterpreted this as meaning that people with learning difficulties should behave according to the norms of society and therefore that their behaviour should be modified until it became more like the norms of society.

Though there was no controversy because the architects were separated by a generation, the same difference of approach existed between George Jepson, the first head of The Retreat in York and John Kitching, the third head. At the start of the nineteenth century George Jepson tried to provide as normal an environment for people with a mental illness or mental disability as possible on the grounds that this would be less stressful for them and aid their recovery; in the middle of the nineteenth century John Kitching argued for behaviour management actively to improve recovery (Digby, 1985). Like George Jepson, Bengt Nirje did not come from a professional background; like John Kitching, Wolf Wolfensberger did.



My thoughts & feelings about Normalization...



An Overview of Social Role Valorization Theory

Joe Osburn

Social Role Valorization (SRV) is the name given to a concept for transacting human relationships and human service, formulated in 1983 by Wolf Wolfensberger, PhD, as the successor to his earlier formulation of the principle of normalization (Lemay, 1995; Wolfensberger, 1972). His most recent (1995) definition of SRV is: "The application of what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defense of valued social roles for people"

(Wolfensberger, 1995a).

The major goal of SRV is to create or support socially valued roles for people in their society, because if a person holds valued social roles, that person is highly likely to receive from society those good things in life that are available to that society, and that can be conveyed by it, or at least the opportunities for obtaining these. In other words, all sorts of good things that other people are able to convey are almost automatically apt to be accorded to a person who holds societally valued roles, at least within the resources and norms of his/her society.

There exists a high degree of consensus about what the good things in life are. To mention only a few major examples, they include home and family; friendship; being accorded dignity, respect, acceptance; a sense of belonging; an education, and the development and exercise of one's capacities; a voice in the affairs of one's community and society; opportunities to participate; a decent material standard of living; an at least normative place to live; and opportunities for work and self-support.

SRV is especially relevant to two classes of people in society: those who are already societally devalued, and those who are at heightened risk of becoming devalued. Thus, SRV is primarily a response to the historically universal phenomenon of social devaluation, and especially societal devaluation. In any society, there are groups and classes who are at value-risk or already devalued in and by their society or some of its sub-systems. (In North America, it has been estimated that from one-fourth to one-third of the population has characteristics that are societally devalued to the point that they exist in a devalued state.) Devalued individuals, groups, and classes are far more likely than other members of society to be treated badly, and to be subjected to a systematic--and possibly life-long--pattern of such negative experiences as the following.

1. Being perceived and interpreted as "deviant," due to their negatively-valued differentness. The latter could consist of physical or functional impairments, low competence, a particular ethnic identity, certain behaviors or associations, skin color, and many others.
2. Being rejected by community, society, and even family and services.
3. Being cast into negative social roles, some of which can be severely negative, such as "subhuman," "menace," and "burden on society."
4. Being put and kept at a social or physical distance, the latter most commonly by segregation.
5. Having negative images (including language) attached to them.
6. Being the object of abuse, violence, and brutalization, and even being made dead.

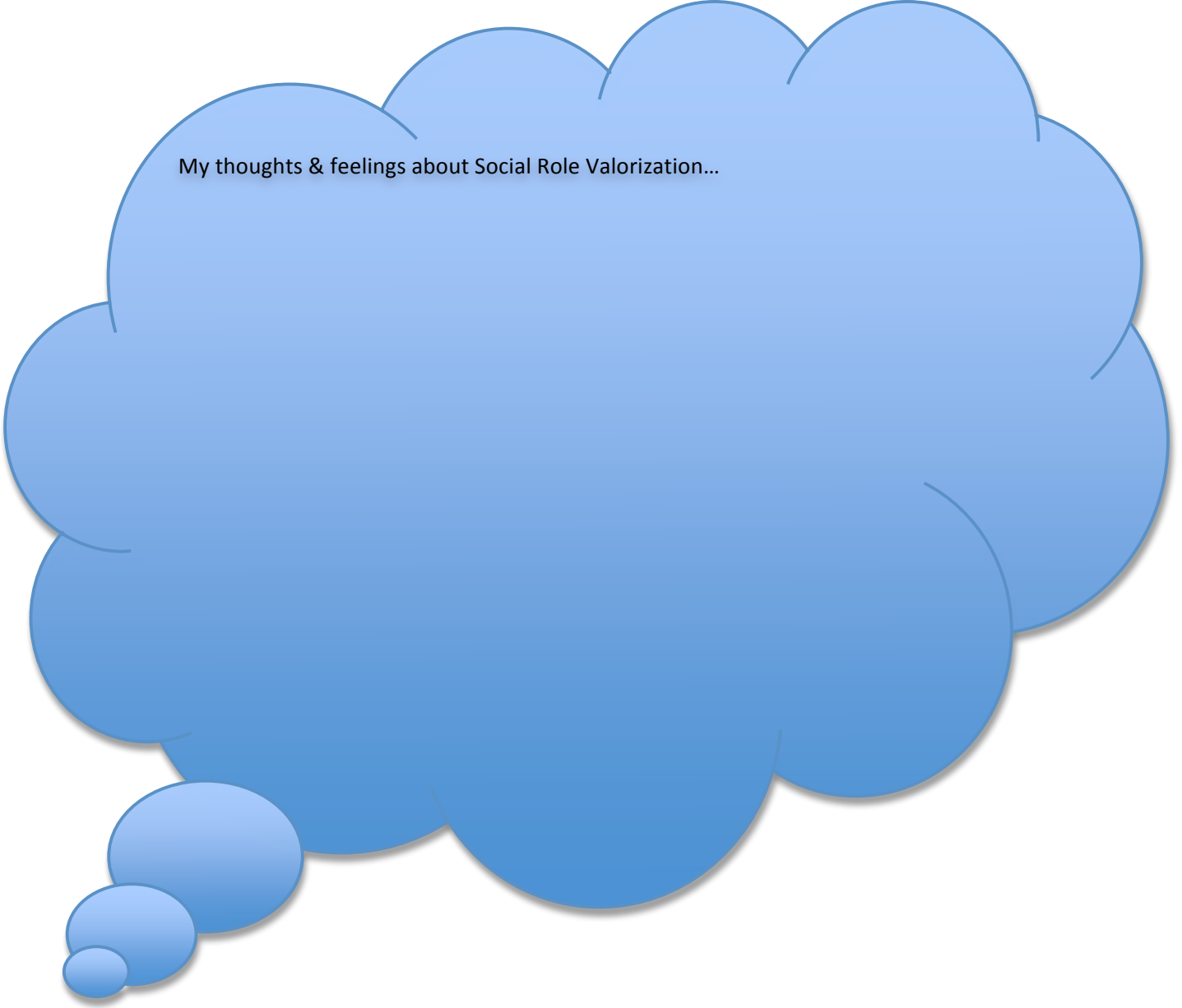
The reality that not all people are positively valued in their society makes SRV so important (Kendrick, 1994). It can help not only to prevent bad things from happening to socially vulnerable or devalued people, but can also increase the likelihood that they will experience the good things in life. Unfortunately, the good things in life are usually not accorded to people who are devalued in society. For them, many or most good things are beyond reach, denied, withheld, or at least harder to attain. Instead, what might be called "the bad things in life" are imposed upon them, such as the six experiences listed above. This is why having at least some valued social roles is so important. In fact, a person who fills valued social roles is likely to be treated much better than people who have the same devalued characteristics, but who do not have equally valued social roles. This is because when a person holds valued social roles, attributes of theirs that might otherwise be viewed negatively are much more apt to be put up with, or overlooked, or "dismissed" as relatively unimportant.

Enhancing the perceived value of the social roles of a person or class is called social role valorization, and doing so is role-valorizing. There are two major broad strategies for pursuing this goal for (devalued) people: (a) enhancement of people's social image in the eyes of others, and (b) enhancement of their competencies, in the widest sense of the term. Image enhancement and competency enhancement form a feedback loop that can be negative or positive. That is, a person who is competency-impaired is highly at risk of suffering image-impairment; a person who is impaired in image is apt to be responded to by others in ways that

delimit or reduce the person's competency. But both processes work equally in the reverse direction. That is, a person whose social image is positive is apt to be provided with experiences, expectancies, and other life conditions which are likely to increase, or give scope to, his/her competencies; and a person who displays competencies is also apt to be imaged positively.

Role-valorizing actions in the image-enhancement or competency-enhancement domains can be carried out on four distinct levels and sectors of social organization.

1. The individual;
2. The individual's primary social systems, such as the family;
3. The intermediate level social systems of an individual or group, such as the neighborhood, community, and services the person receives;
4. The larger society of the individual or group, including the entire service system.



My thoughts & feelings about Social Role Valorization...