A Quarter-Century of Normalization and Social Role Valorization

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Published by University of Ottawa Press

Flynn, Robert J. and Raymond Lemay. 
A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact. 

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The original "Scandinavian" Normalization principle and its continuing relevance for the 1990s

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1 INTRODUCTION

The Normalization principle emerged from Scandinavia in the late 1960s. It was first published and circulated in 1969 (Nirje, 1969). Since then, it has had a profound effect around the world. It has greatly advanced opportunities for all people, including people with a mental handicap as well as with other forms of disabilities, to be able to live in the community on the same basis as everyone else. It has also served to redirect social policies and the nature of service provision in order to make "normal" living possible.

This paper discusses the nature of the Normalization principle, as it originally emerged from Scandinavia, along with its major characteristics and implications. The principle has been subject to numerous misinterpretations, as well as confusion with the version of Normalization (and its successor, Social Role Valorization) later developed by Wolfensberger (see Perrin and Nirje, 1985, for a more comprehensive discussion of misconceptions of the Normalization principle). Thus where it will help in clarification, it occasionally clarifies what the principle is not, as well as identifying essential differences from Wolfensberger's version.

In my view, the principle is every bit as relevant now as when it was first formulated some 25 years ago. To help explain both the meaning of the principle and its implications, I will discuss some current examples of the principle at work, drawing in particular upon my own experiences and other developments within Canada.

2 GENESIS OF THE PRINCIPLE

The Normalization principle gradually emerged over a period of time in Scandinavia.¹ It was first applied with respect to people with mental handicaps, but later broadened to apply to people with any form of disability.

In the 1960s, Bengt Nirje served as executive director and ombudsman of FUB, the Swedish Association for the Developmentally Disturbed. In this capacity, starting in 1962, he was active in the development of a new Swedish law, which eventually came into being in 1968.

Meeting in Copenhagen in 1963 with Niels Erik Bank-Mikkelsen, Nirje reviewed the 1959 Danish law, for which Bank-Mikkelsen had been a driving force. Nirje was struck by the words in the preamble: "to let the mentally retarded obtain an existence as close to normal as possible." Neither the terms "Normalization" nor "principle" emerged until some time later. But this was the starting point for discussions where Nirje and some of his colleagues, most notably Bank-Mikkelsen and Karl Grunewald of Sweden, increasingly used the word "normal" as a means of describing how living conditions should be for people with disabilities.
The roots of the concept of Normalization can be traced to the development of the modern social welfare society in Sweden in the late 1930s and 1940s (e.g., Billimoria, 1993; Pedlar, 1990). Swedish social welfare policy was based upon principles of equality and the right of all people to live in society and to be guaranteed a good standard of living. It also recognized the obligation of the state to provide social services, if necessary, to make this possible. Normalization emerged from this context of egalitarianism. As far back as 1946, a government “Committee for the Partially Able-bodied” said, in the context of employment, that people with mild disabilities “should as far as possible be included in the ordinary system of social services which is under development in our land” and even spoke of “Normalization” (Ericsson, 1992). But the committee did not concern itself with those with a more severe handicap who were relegated to institutional care. The work of this committee, however, was not publicized, and was uncited and unknown when the Normalization principle later came to be developed in the 1960s.

Thus Nirje can be considered responsible for the modern development and statement of the Normalization principle. He gradually developed his ideas through discussions with colleagues and lectures in Scandinavia, and also during a lecture tour in the United States in 1967. In 1968, he presented his landmark paper “The Normalization Principle and Its Human Management Implications” in Washington to the President’s Committee on Mental Retardation, which was published by the committee the following year (Nirje, 1969)—the first formal published statement of the Normalization principle, in any language. Only later was the Normalization principle translated back into Swedish and Danish!

Let me take this opportunity, right now, before going any further, to clear up any possible misunderstandings. The principle, in its original version, is not a museum piece or obsolete. It was not replaced by the later Wolfensberger version of the principle, as Wolfensberger, for example, asserted (e.g., Wolfensberger, 1972), which differs from it in many essential respects (e.g., Billimoria, 1993; Emerson, 1992; Perrin & Nirje, 1985; Wolfensberger, 1980). Nor did “Scandinavian” Normalization stop developing and evolving after 1969. Indeed, Nirje and many others, in Scandinavia but also in other countries around the world, have continued to refine, explain, and apply the principle, as well as carry out research documenting its impact on quality of life.

I am also uneasy about referring to the original version of Normalization as “Scandinavian.” Indeed, the principle emerged from Scandinavia, in particular, from Sweden and Denmark. But, as Nirje has indicated throughout his writings (e.g., Nirje, 1993), it is universal in its implications, relevant in all cultures and societies, and it has been applied in many different countries around the world. And while the original Normalization principle has greatly influenced successively more community-oriented pieces of legislation in Scandinavia (e.g., Billimoria, 1993; Hollander, 1993; Pedlar, 1990), it has never totally dominated policy (e.g., Bank-Mikkelsen, 1976b). In Scandinavia, as elsewhere, the principle has been controversial and there is a divergence of views.

And, as noted above, Normalization, as defined by Nirje, was first published in English, in the United States, by no less an authority than a committee established by the President of the United States. The “Scandinavian” version of the principle was widely publicized by this American committee and played a major role in the redirection of social policy regarding services for people with mental handicaps within the United States and elsewhere. Thus as Dybwad (1982) has said, the Nirje definition should, at the very least, be considered an alternative “North American” orientation. Hence my use of quotes in speaking of “Scandinavian” Normalization.

3 WHAT IS THE NORMALIZATION PRINCIPLE?

The Normalization principle was originally defined by Nirje (1969) as: “Making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.”

Most recently, Nirje (1985) rephrases this as: “Making available to all persons with intellectual disabilities or other handicaps, patterns of life and conditions of everyday living which are as close as possible to or indeed the same as the regular
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In the UK, they talk about the Ordinary Life movement. This means that people, even with severe disabilities, “can (and should) live their lives in the community like anyone else” (Ward, 1992). The means of achieving this include: “ordinary houses in ordinary streets, ordinary jobs in ordinary workplaces, ordinary friends, neighbours, social and leisure opportunities, with whatever support is needed to enable this to happen” (Ward, 1992).

The essence of “Scandinavian” Normalization is really quite simple. As Nirje and Bank-Mikkelsen have emphasized since the principle was first stated, it means no more—or less—than the right of people with disabilities to live their lives on the same terms as anyone else in society, along with the necessary supports to make this possible. It means that “disabled people should be part of the community and live together with other people” (Hollander, 1993). It means that all people with disabilities have the right to normal community conditions of life and the same rights to equality, to be different, and to be respected as anyone else in society.

As Nirje indicates, the principle with its eight facets serves as an instrument at four different levels:

1. **At an individual level**, providing guidance for persons responsible for people with disabilities about “how to meet a problem, how to advise, how to plan actions, and what to do” (Nirje, 1985).

2. **At the community level**, providing guidance for “the development or refinement of the educational and social services required and for an understanding of the needed training, support and cooperation of the various specialized staff” (Nirje, 1993).

3. **At the societal level**, providing guidance for the development of legislation and policies and the structure of services.

4. **At the cultural level**, serving as an instrument for understanding and analyzing “the changes gradually taking place in the patterns or culture or conditions of life affecting not only persons with intellectual or other disabilities . . . but also other groups in society.” Normalization, as it emerged from Scandinavia, was never intended to be an “ism” or a comprehensive theory and set of strategies. It was never intended to be a dogma. Indeed, as Bank-Mikkelsen (1976a, 1976b, 1976c) states, it is an “antidogma,” saying that we do not need special theories for people with mental handicaps or with other
circumstances and ways of life of society” (italics in original). This revised definition reflects the applicability of the principle to all persons with disabilities. It gets away from the terms “norms” and “mainstream,” which have been misunderstood and misused. And it puts “as close as possible” into context, implying that people with disabilities have a right to live in society on the same basis as anyone else.

As Nirje has indicated throughout his writings (e.g., Nirje, 1993), normal patterns of conditions of life can be viewed in terms of eight different facets or elements:

1. A normal rhythm of the day.
2. A normal rhythm of the week.
3. A normal rhythm of the year.
4. The normal experiences of the life cycle.
5. Normal respect for the individual and the right to self-determination.
6. The normal sexual patterns of one’s culture.
7. The normal economic patterns and rights of one’s society.
8. The normal environmental patterns and standards in one’s community.

Bank-Mikkelsen (1976c) has described Normalization as the “acceptance of the mentally retarded with their handicap, and offering them the same conditions as are offered to other citizens” (italics in original). It means making normal housing, working (including training and education), and leisure conditions. Bank-Mikkelsen adds that “the Normalization principle simply means that all citizens shall have equal access to the same benefits,” that people with disabilities have the right to the same services and facilities that are open to others. They are “ordinary people with ordinary civil rights who happen to have a handicap” with “the legal and human rights of all other citizens” (1976b). He also indicates that:

[Normalization] means that mentally retarded people should not be treated in any special way . . . . This, of course, does not mean that mentally retarded and other handicapped people do not have a right to special education or special treatment. But this should be provided according to need and not merely because they are mentally handicapped and the same should apply to other citizens who need special provision for a short period of time or for their whole lives (1976b).
disabilities, but rather equality. It was developed as a response to the dogma of protectionism. Thus Normalization was not intended as an all-encompassing directive with specific do’s and don’ts. It is silent, for example, about the appropriateness of specific forms of treatment, provided that they are consistent with advancing the goal of Normalization.

“Scandinavian” Normalization is a general philosophy about how we should view human beings. It is a guiding principle that provides a direction for social policies. It is a general approach that should be straightforward and easy to understand. It has been subject to misinterpretation, partly due to basic disagreements with its assumption that people with disabilities can and should have the right to live in the community, but also partly due to well-intentioned but misguided attempts to overcomplicate it and to be overprescriptive.

The Normalization principle first evolved in the days of institutions. Some of the ideas leading to its development grew out of analyses of living conditions within institutions. As noted above, a major initial reason for the development of the principle was to counter the dogma of protectionism, which was used to support and defend institutions. Normalization is a relative concept and one of its uses, especially in its early days when institutional settings were the norm for people with mental handicaps, has been to improve conditions within institutional and quasi-institutional settings.

For this reason, there has been some misunderstanding that the Scandinavian version of the principle endorsed institutionalization (e.g., Emerson, 1992; Wolfensberger, 1980). But this is just not so. Community living for people with disabilities, on the same basis as others, has always been the goal of Normalization. It has always supported the concept that regular community services should be available to everyone, including to those who happen to have a disability. Nirje and Bank-Mikkelsen, in their writings and public addresses, have always made clear their strong opposition to institutions. The phasing out of institutions in Sweden, Denmark, much of North America, and elsewhere is fully consistent with the principle. Indeed, as Dybwad (1982) points out, the principle played a major role in influencing a number of judicial judgments to close down institutions within the United States.

4 NORMALIZATION AND THE PRIMACY OF RIGHTS AND SELF-DETERMINATION

The Normalization principle, as it originated in Scandinavia, first and foremost, is rooted in a strong sense of equality for all people within society, including those who happen to have a disability. A concern for rights is—and always has been—paramount. Indeed, Bank-Mikkelsen (1976c) has said: “The Normalization principle does not by itself stand for anything else than the idea that the handicapped . . . shall have the same rights and obligations as other citizens.”

As Nirje has emphasized (for example, in a paper discussing the basis of the Normalization principle), human rights and normal respect for the integrity of the individual “form a basis for all the other facets of the Normalization principle” (Nirje, 1985). In his chapter in this volume, he indicates how his formulation of the principle in 1968 closely followed the 1967 Stockholm conference of the International League of Societies for Persons with Mental Handicaps (ILSMH) which led to the declaration of the rights of people with mentally handicaps at the league’s Jerusalem Congress, with the theme “From Charity to Rights,” the following year. This, in turn, led to the UN Declaration of the Rights of Persons with Mental Retardation in 1971 and the subsequent UN Declaration of the Rights of Disabled Persons in 1975. All these documents contain the word “normal” in referring to conditions of life for people with disabilities and also incorporate the philosophy of “Scandinavian” Normalization.

Let me repeat this point. Normalization is—and always has been—about rights. As Bank-Mikkelsen (1973) puts it: “The principle of Normalization [means] that all human beings are equal and that all human beings are entitled to the same rights.” Everything else follows from this crucial point.

Rights mean self-determination. This means that people have the right to decide for themselves what they want to do with their lives. This means that people with disabilities have the freedom to live a life based on the same values and on the same terms as others in society. This means that they have the freedom to choose among a range of options, life circumstances, patterns of life, and opportunities on the same basis as do others. A focus on rights implies consideration for
quality of life, as people view and define this themselves. This has major implications for human services and for the role of professionals. Normalization does not mean making people normal. It does not mean that the behavior of people with disabilities needs to be normalized or made to conform to any particular standard. It does not involve some people deciding, however benevolently, what is best for others. It does not include dictating which standards or conditions of living, or which particular roles are or are not appropriate for people with disabilities. This represents a major area of misunderstanding, and of disagreement between the “Scandinavian” and Wolfensberger versions of Normalization.\(^2\)

The Nirje definition of Normalization, presented earlier in this paper, talks about making available to people. As Nirje (1985) says: “The principle starts with respect for the integrity of the individual and does not simply mean by manipulation ‘to establish, enable, or support behaviors, appearances and interpretations which are as culturally normative as possible’ (Wolfensberger, 1972).” “Scandinavian” Normalization emphasizes the primacy of individual preferences. Wolfensberger (1972), in stark contrast, says that “normalizing measures can be offered in some circumstances, and imposed in others.”

Indeed, as Dybwad (1982) says: It is normal to be different. As Bank-Mikkelsen (1976b) puts it: “A mentally retarded person is not normal—who is? What is normality, and does anyone want to be ‘normal’ at a time when there is so much understanding for people who are trying not to be uniform?” Indeed, the watchword of the 1990s is “diversity”—in North America, Europe, and around the world. Businesses, for example, are spending huge sums of money in training, reflecting an increasingly diverse workforce and a diverse population and a recognition that diversity is not only here to stay, but can have many advantages. Why would human service workers deny people with disabilities the right to be themselves?

Nondisabled people have the right to define which social roles they themselves value and to decide which of these, if any, they would like to emulate. They have the right to alternative lifestyles, including to those which may be rejected by many others. The principles of “Scandinavian” Normalization and of self-determination say that people who happen to have a disability should have the same right. There are alternative lifestyles and routes to empowerment other than conformity to the most conservative options in society, as implied by the conservative corollary in Wolfensberger’s definitions of Normalization and Social Role Valorization. People with disabilities should have the right to choose for themselves how they wish to live and to what extent they wish to emulate the pillars of society. This is in stark contrast to Social Role Valorization, which asserts that “Valued social roles for people need to be attained and preserved in order for them to be or become [more] positively valued socially” (Wolfensberger, 1992).

Everybody, no matter how severe their disability, is capable of expressing preferences in some way. It may, however, require extra effort on the part of others to understand these desires. As Nirje (1976) has said, we need to give “sensitive attention to those who do not speak or have difficulty in expressing themselves.” Normalization implies “normal respect and understanding for the silent wishes as well as for expressed self-determination of people with disabilities.”

Many people may have difficulty at first in making their own informed choices. This is hardly surprising for those who have been used to a lifetime of others making decisions on their behalf and who have had little exposure to the range of options that are available. The appropriate role of service providers, in these instances, is not to act as substitute decision makers. Rather, “individuals should be encouraged and assisted in expressing their own preferences and making their own choices; Normalization implies that opportunities and training should be provided to assist in this process” (Perrin & Nirje, 1985). For people who have difficulties in actively voicing their own preferences, the role of advocates should be to help them to do so as much as possible and where necessary, to speak on behalf of the choices and desires that people with disabilities have themselves expressed. The success of People First has demonstrated that labeled people, given the opportunity, can be perfectly capable of speaking for themselves.

To tell people what they must do, what is “best” for them, however benevolent one’s intentions, without respecting their own feelings, is authoritarian. As Brown and Smith (1992b) say: “Any situation in which
an individual or group's subjective experience is discounted in favour of an 'objective' account of what they feel, think or want clearly signals an abuse of power." Perrin and Nirje (1985) describe this as "an unwarranted abuse of the powers of the therapeutic state."

5 THE ENVIRONMENT, NOT NECESSARILY THE INDIVIDUAL, NEEDS TO CHANGE

Consumers—people with disabilities—are demanding the right to live in the community, with their disabilities, on the same basis as others. They are demanding a society that allows them to be themselves, like other people, and which accommodates their disabilities and special needs. They are demanding a society in which all public facilities and opportunities are accessible to them and appropriate for their needs and abilities.

"Scandinavian" Normalization, arising as it does from a context of equality and respect for self-determination, has been saying exactly this for 25 years. It calls for Normalization of the conditions of life, not of individuals, their behavior or appearance. As Bank-Mikkelsen (1976c) says, Normalization means the acceptance of people in the community with their handicap.

Nirje (1985) has defined integration as: "to be yourself—to be able and to be allowed to be yourself—among others." Nirje (1980) has distinguished among six different forms of integration. The mere physical presence in the community does not, by itself, constitute either true integration nor represent Normalization. As we all know by now, dumping people "in the community" without the provision of necessary support does not result in anything other than the appearance of integration. A prerequisite to true integration is a society that accepts people as they are.

It is interesting to note that, as Hutchison (1986) has indicated, when professionals plan programs they tend to identify problems in individuals that keep them from fitting in. In contrast, when people with disabilities are involved in planning, they tend to identify barriers in the ways programs are structured and offered that prevent them from participating. For consumers, barrier removal is key to being able to be part of the community.

As Hollander (1993) says:
A disability is not a characteristic of a person but a relationship between the person and the environment. A disability is relative in this sense. This is important because it places the responsibility on the environment rather than on the person. All activities in the society have to be accessible to everyone, including disabled people, thus preventing a disability from becoming a handicap.

This has profound implications. Specifically, the assumption inherent in Wolfensberger's version of Normalization and Social Role Valorization that individuals must change to blend in or "pass" in society or that they need to conform to someone else's idea of what constitutes acceptable or valued behavior, and at the most conservative end at that, was never part of "Scandinavian" Normalization. Indeed, it is contrary to the precepts of equality and self-determination. As Nirje (1985) says, "Scandinavian" Normalization "deals with realities of life, not with appearances of conformity and passing, hiding what some call deviancy." What needs to be "normalized" are not individuals, but the environment and opportunities, in order to accommodate people with their differences and unique needs.

Most societies are full of people with different beliefs and values, with different views of life, with different standards of behavior and of "appropriate" dress, and so on. Almost every society tolerates some downright eccentrics. What are considered "valued social roles" is changing. Former pillars of society, including prominent newspaper publishers (e.g., Conrad Black), leading business people (e.g., the Reichmanns in Canada or Schneider in Germany), high-ranking politicians (e.g., Canada's former prime minister Brian Mulroney), and royalty (e.g., Prince Charles) have fallen off their pedestals, at least in the eyes of many people.

Ironically, these days, it is often those at the most conservative end whose values have been questioned the most. Today's heroes take a wide variety of forms, from across the full spectrum of society. They, for example, may be female or male, from any social background, and may or may not wear a coat and tie. They can just as easily be a single mother on welfare who has helped her community. (e.g., One such "hero" is discussed in Osborne and Gaebler's [1992] influential book Reinventing Government.)
would human service workers tell people with disabilities that they need to conform to any given standard of behavior (or dress), particularly to standards that are increasingly coming into question?

Some people with disabilities may be able to disguise the nature of their disability, at least at times. But as Brown (in press) says: “The reality is that people who are different, particularly if they look different, cannot blend in.” And why should they—in order to be entitled to the same rights as others? This is contrary to the original Normalization principle, which means the acceptance of people with their differences, with their disabilities in a society which accommodates all people, including those with special needs. As Nirje (1993) has indicated, “Scandinavian” Normalization has its basis in “the recognition of the right to be different and to have the same right to be respected as anyone else.”

As Brown and Smith (1992b) and others have observed, other minority groups have rejected assimilation or mimicking “socially valued roles” as a route to equality. For example, the women’s and black power movements now recognize that empowerment comes from asserting, rather than hiding, their differences. Self-assurance, confidence, and power come from taking pride in who they are. They demand the right to full participation in a society that welcomes and accommodates them with their differences. Moreover, saying that people with disabilities have to conform to the roles, culture, and expectations of the dominant group within society serves to reinforce rather than to challenge the inappropriate dominant ideology (Dalley, 1992). As Nirje (1985) has observed, “the concept of deviancy seems to be based on accepting prejudice as a ‘normal’ social occurrence—a peculiar culture-bound phenomenon.”

But what about competence? Do not people with disabilities need to increase their competence? Of course. But the key is, who decides. Ericsson (1992) contrasts what he refers to as the competence and the citizen perspectives. The former, which derives from institutional patterns of service but has been carried over into professional-run community services, focuses on a person’s deficiencies as defined by someone else. With the citizen perspective, in contrast, the starting point is what an individual wants to do. The individual’s “own views are needed to express in what respect, under what conditions and by which means the person’s competence is to be increased” (Ericsson, 1992).

Furthermore, independence—and competence—comes when people make their own decisions about how they wish to live. The way to help people become independent is to assist them in learning how to make their own decisions, rather than to dictate to them standards of behavior that they must follow.

6 EXAMPLES FROM CANADA

Is it pie-in-the-sky, or unrealistic, to assert, in accordance with the “Scandinavian” Normalization principle, that the physical and social environment—indeed society itself—must change to accommodate people with disabilities? To be sure, there is a long way to go. But major strides are being made. Indeed, all progressive legislation, social policy, and program development now are concerned with ways of accommodating people with disabilities in the community and in regular community services.

Let me give some examples from Canada. Judge Rosalie Abella, in her highly influential *Equality in Employment: A Royal Commission Report*, states that:

To treat everyone the same may be to offend the notion of equality. Ignoring differences may mean ignoring legitimate needs. It is not fair to use the difference between people as an excuse to exclude them arbitrarily from equitable participation... Ignoring differences and refusing to accommodate them is a denial of equal access and opportunity. It is discrimination. (Abella, 1984)

Canada’s constitution, since 1985, provides for equal protection and equal benefit of the law without discrimination based upon mental or physical disability as well as other factors such as gender, race, and so on. In a recent decision of the Supreme Court of Canada (1989), the Court affirmed that equality does not mean sameness since “identical treatment may frequently produce serious inequality.” The Court further stated that:

Recognizing that there will always be an infinite variety of personal characteristics, capacities, entitlements and merits among those subject to a law, there must be accorded, as nearly as may be possible, an equality of benefit... A law expressed to bind all should not because of irrelevant personal differences have a more burdensome or less beneficial impact on one than another.
Similarly, human rights legislation, such as Ontario’s Human Rights Code, requires all publicly available facilities and services to provide “reasonable accommodation.” This means that both public and private services and facilities need to accommodate the special needs of people with disabilities, up to the point where this would involve “undue hardship.” Canada has had employment equity legislation with respect to federally regulated businesses for some time. While this legislation has been criticized for being weak, Ontario has just put somewhat stronger legislation into effect. This legislation requires public and private workplaces to carry out “employment systems reviews” to identify systemic barriers to employment and to demonstrate “reasonable progress” toward the achievement of employment equity.

In other words, there is a legal onus in Canada to accommodate people with disabilities to modify the physical and social environment as necessary to provide for full participation.

In Canada, the federal government and all the provinces and territories recently undertook a joint review of services affecting Canadians with disabilities, entitled “Mainstream 1992,” with the objective of developing “a collective strategic framework which explores from a social perspective the full integration of Canadians with disabilities in the mainstream of Canadian society.” The final report (Pathway to Integration) of the review articulates a vision in which Canadians with disabilities could participate fully in society. It identifies the three key principles of equality, empowerment, and full participation. Strategic directions identified include: the provision of disability-related supports that people with disabilities need to participate in the community and provide for their own well-being; mainstream sectors that are fully accessible; social services playing an educative and facilitative role; removal of barriers in the workplace that prevent people with disabilities from being employed; and increased consumer participation, including moving toward individualized funding models in social services.

To give a couple of examples from other jurisdictions, the Americans With Disabilities Act spells out the obligations of all publicly available services and facilities in the United States, including, for example, employment settings, transportation and communications, and leisure settings, to take whatever steps are necessary in order to make them available to people with disabilities. New Swedish legislation places responsibility on the environment rather than on the person (Hollander, 1993).

These and related legislative and policy steps have not ended all discrimination, of course. But they are important forward steps. Physical accessibility is easier and more commonplace than changes required to address more systemic and invisible barriers to participation. For example, curb cuts and building codes that require all facilities intended for the use of the public to be physically accessible are now commonplace.

But, partly as a result of the visibility of more and more people with disabilities in the community (so much for the “advantage” of “blending in”) and as a result of the insistence of consumer advocacy groups (so much for the “advantage” of not associating with other “devalued” people), there are many examples where attitudes are changing.

An excellent example of how the public is now willing to accept people with visible disabilities comes from a recent election campaign in Canada. An ad from the then government in power attacked Jean Chrétien, leader of the Liberal Party, not for his policies, but for his visible impairment. It showed a close-up of him speaking with the camera focused on his mouth, which is paralyzed on one side from a childhood illness, and asked if we wanted “this man” to represent Canada. The universal reaction to this ad, for daring to ridicule handicapped people, was one of outrage. It has been credited as being the decisive moment in the election campaign, which ended with Chrétien becoming Prime Minister with a comfortable majority (Smith, 1994).

There are many good examples of community-based services that have examined all their programs, activities, facilities, and ways of operating, often in cooperation with disability organizations, in order to identify and to address both overt as well as invisible or systemic barriers to participation. Let me illustrate this with some examples from the leisure area, although I could just as easily speak of developments concerning housing or employment.

I have recently completed a major research study, examining innovative approaches across Canada and beyond, which culminated in a guide to how community recreation and disability agencies can
enable people with disabilities in regular leisure and recreation (Perrin, 1992; Perrin, Wiele, Wilder, & Perrin, 1992). We found many successful approaches. To cite just a couple of examples, one Ontario recreation department has a “Barrier Breakers” program, which does not hesitate to help solve any barrier to participation in recreation, including barriers such as transportation. The departmental staff will provide other forms of assistance, for example in introducing individuals to a range of different activities. Anything goes, from having coffee in the mall to joining in a more structured recreation program. Other recreation departments offer an activity sampling program to young adults. One department will even help form “friendship circles” where lack of a support network is keeping a person from engaging in recreational activities.

Some programs use a variety of strategies to assist people who say they do not feel welcome when participating in integrated recreation. In some places, a coparticipant will meet a new participant with a disability, showing them around and working together if any assistance is required, for example in activity modifications or interpretation of instructions.

We found strong interest among municipal recreation authorities in learning how they can include more people with disabilities in their programs. In general, however, we found stronger resistance to community integration among social service agencies, many of whom were reluctant to “let go” of their segregated services. But we also found positive examples. In southwestern Ontario, a number of different agencies have formed a Community Involvement Council, which jointly discusses how they can support people in using the community, including many people who have spent much of their lives in institutions. Some agencies have undergone reorganization, and now, instead of providing segregated services, use their staff to help individuals take advantage of regular leisure opportunities in the community.

7 ROLE OF SUPPORT SERVICES, INCLUDING “SPECIAL” SERVICES

The “Scandinavian” Normalization principle supports, indeed insists upon, the right to whatever services, training, and support are required to permit regular living conditions in the community. In contrast with Wolfensberger’s reformulation, these services may or may not be “normative.” Special or “unnormal” services are fully appropriate, as long as they support the objective of “ordinary” living and full participation in the community.

Everyone needs assistance of some kind in order to live in the community. None of us, unless we are total hermits, are truly independent of others. Everyone makes use of a variety of forms of assistance—some personal and informal, others formal and/or purchased. What constitutes “special” services? Generally, these are defined as services that are used by a minority of people. But an accommodating society recognizes that everybody is unique and that everybody needs “special” assistance from time to time.

For example, as Perrin and Nirje (1985) indicated: “A person with heart trouble may consult a cardiologist; in extreme cases, a pacemaker, a decidedly “unnormal” foreign body, may be surgically implanted in the body. The purpose of this abnormal treatment is to permit the continuation of everyday living patterns (i.e., ‘normal’ living).” Someone who happens to have a disability should have the same right to whatever “special” services are needed to permit “normal” living.

This is consistent with consumers demanding access to services that enable them to participate in the community on the same footing as others. For example, the Council of Canadians with Disabilities (formerly COPOH), the national crossdisability consumer association in Canada, has said, “Equality of opportunity does not mean ‘same treatment’ but rather the development of programs and services which address the disadvantages most experienced by persons with disabilities.”

As discussed earlier, the Canadian constitution, Judge Abella, and human rights and employment equity legislation all recognize the need for special or different treatment in order to result in equality of benefit. Indeed, as Abella has said, to do otherwise is discrimination.

Let me be very clear. People with disabilities need disability-related services and assistance in order to live a life with some semblance of normalcy, in order to be able to take advantage of regular community-based opportunities. Some people may require only a minimum amount of support on occasion. Others may require more intensive support on an ongoing basis.
It is absurd to say that use of such services, including visible aids, are not appropriate because they are “devaluing.” For example, the Wolfensberger version of Normalization and Social Role Valorization says that a person with a hearing impairment should not use a visible hearing aid, that washrooms in residences should not have grab bars. People with disabilities are now demanding the right to make their own decisions about whether or not they will use aids and make their disabilities visible. As noted earlier, Jean Chrétien was elected Prime Minister of Canada in spite of, or perhaps partly because of, his facial impairment.

Consumers now are demanding control over the services that they need in order to live independently in the community. For example, they are demanding the ability to choose which services and service providers they want to use and control over funds to purchase these directly. They are also demanding the right to direct how these services should be provided, at both the individual and the policy level. Models providing for such consumer control or individualized purchase of services are now being developed. This, incidentally, contrary to Wolfensberger’s claim, suggests that paid services, at least under certain circumstances, can work to the benefit of the consumer.

Proponents of “Scandinavian” Normalization have been described as supporting segregated services (e.g., Emerson, 1992; Wolfensberger, 1980). To the extent that they do not reject out of hand any form of service that leads to the goal of Normalization is consistent with the principle, there is some truth to this. But it is important to view this in context. Normalization, as mentioned earlier, is silent about the appropriateness of specific treatment modalities. “Special” services that support the ability of people to participate in society are consistent with the principle. But they are not appropriate when they isolate or otherwise separate people from the community.

For example, Bank-Mikkelsen, one of the fathers of Normalization, says: “It is a mistake to adopt any particular strategy for all persons” and “in some cases, segregated, intensive programs may be best suited” for some individuals (Bank-Mikkelsen, 1976a). But he also said, back in 1976: “In the near future, Denmark will show that no special service is needed to take care of the mentally retarded” (Bank-Mikkelsen, 1976b); and “The ordinary authorities of society must serve all citizens; some need more help than others, but nobody should be left out—this also means Normalization” (Bank-Mikkelsen, 1973).

This means, as Bank-Mikkelsen indicated, that regular community (or mainstream) services should be open to everyone, including people with disabilities, and should accommodate any special needs. I just provided some examples of how this can work in the leisure area. The challenge is to address barriers to “normal” living in a way that in turn does not create other barriers. In most cases, the only special services that are now appropriate are those that support the ability of people to use regular community services. Segregated, parallel programs for people with disabilities are rarely necessary. They are harmful in that they not only isolate people from the community; they, in common with institutions, indirectly “teach” skills (e.g., passivity, going along with what others think is best rather than learning how to make one’s own decisions) that are the opposite of what are needed to live independently.

Twenty years ago, even 10 years ago in some places, when Normalization was still a controversial concept, the major focus was keeping people with disabilities from going into institutions and enabling people within institutions to enter the community. This battle is now being won. It is now necessary to address less obvious forms of segregation that keep people from true integration and full participation in the community. For example, there is now little need for specialized “separate but equal” programs such as sheltered workshops, congregate living, or segregated recreation. There is ample evidence, including from my own research, illustrating the superiority of alternative models such as supported employment and supportive housing.

One important development involves the increasing use of natural supports. In this model, support workers help people with special needs to develop connections with others. For example, a coparticipant in a recreation program or a coworker in an employment setting may be encouraged to provide assistance when required, sometimes on a completely volunteer basis, sometimes with some form of compensation. Sometimes, arranging for “natural support” is as simple as asking. Consider the following examples from a recent publication of the Community Involvement Council of southwestern Ontario (1993):
Delia needed a ride to the pool. I approached Delia's neighbour, and they went to the pool together. As I look back now, thank goodness I wasn't given any staffing resources. Delia and her neighbour gained a friendship which they still have today.

Isaac kept going over to another table in the restaurant where a woman was sitting alone. She responded warmly. Blaine [the worker] tried to encourage Isaac to come back to their table, but he was pretty insistent. Finally, Blaine approached the woman and asked if Isaac could join her for dinner. She said, "Yes." Blaine was pleased the two were getting to know each other. He went back and had dinner alone!

8 THE NORMALIZATION PRINCIPLE AND THE CONSUMER MOVEMENT

The most important development in the 1990s in the disability area is the growth of the consumer movement. Consumers with disabilities the world over are no longer willing to accept others deciding on their behalf what is best for them. As Mike Oliver makes very clear in his chapter in this volume, people with disabilities are demanding the right to make their own decisions about what services they need and on what basis these should be provided. They are demanding the right to what they feel are essential services to enable them to participate fully in the community. For example, this was a theme in the Third International People First Conference held last year in Toronto, which had representatives from 32 different countries. This was the major focus of Independence '92, an international conference in Vancouver organized by and for people with all forms of disabilities that drew thousands of people with disabilities from numerous countries around the world.

Consumers are increasingly getting together with others to assert their rights. For example, the Council of Canadians with Disabilities (formerly COPOH) represents people across Canada with all forms of disabilities. The disability movement is increasingly cooperating with other movements, such as the women's movement and organizations representing Aboriginal people and racial minorities, in its fight for rights.

As Nirje states in his chapter in this volume, "From Charity to Rights" was the theme of the ILSMH Jerusalem Conference in 1968, a key year for rights around the world, as evidenced, for example, by the French student revolt and demonstrations in the United States about its participation in the Vietnam War and its implications for the democratic process. That same year Nirje drafted and first presented the Normalization principle. This is a critical point. In the 1990s, any approach to human service that does not respect the right of consumers to decide for themselves what they want is no longer legitimate.

"Scandinavian" Normalization, given its grounding in rights and on self-determination, has always been strongly supportive of consumer action at all levels. For example, unlike Wolfensberger's definition of Normalization and Social Role Valorization, which views it as devaluing for people with disabilities to associate with other disabled people, it recognizes that it is normal for people to associate with their peers, such as through social bodies whose members share common interests, goals, and life experiences.

Nirje (1972) acknowledges that there can be a danger of segregation with self-directing groups consisting entirely or substantially of people with disabilities. But he says that this danger must be balanced against important functions these groups serve. For example,

Through these bodies, common feelings and needs can be shared and expressed, and common demands formulated. . . . [They provide] an opportunity for social interaction and self-expression which otherwise may not be available in the same quantity or quality. . . . [They also serve as] an essential media for bringing about greater integration, by providing occasions of sharing in the social life of the community.

And perhaps most importantly, such groups provide opportunities for self-assertion.

People First members have said similar things to me. For example, they say that they feel comfortable participating in People First meetings and enjoy the understanding and support from their peers. They feel that participation is a way to increase their confidence and social skills, which some of them may then be able to use in other settings. And People First provides an opportunity for them to express their own views about
the quality of their lives and about services that are offered to them.

As far back as 1965, Sweden has had leisure clubs, consisting mainly of people with mental handicaps. These clubs quickly took on an expanded, advocacy role, enabling members to express their views about the quality of their lives, their aspirations, and what they felt about the services they were using. Regional and national conferences have provided further opportunities for self-expression and advocacy. For some time, programs and services (e.g., special schools, group homes) in Sweden and Denmark have been required to establish councils to provide an opportunity for consumers to play a role in deciding the way in which services are provided.

In conjunction with the "Mainstream 1992" review, I reviewed statements prepared by consumers and consumer organizations across Canada. A very consistent theme emerged from this review. Consumers, irrespective of the nature of their disability, indicate their desire to live and participate in the community. They identify barriers preventing them from doing so. But they say that one of the greatest barriers to independence are disability services themselves, which they describe as "the problem rather than the solution" to them.

Consumers do not appreciate being treated as charity cases. More than anything else, they bitterly resent "professionals" deciding what is best for them. They want to make their own decisions. They resent being told what is wrong with them, when what they see are barriers, created by others, that turn their disabilities into handicaps and that prevent their full participation in society.

Consumers are demanding the right to determine not just what services they receive at an individual level, but also the right to participate in deciding policies that affect them and how services are to be organized and delivered. They need to be given the opportunity to play a major role in decision making at three levels: a) individual, b) policy, and c) program.

8.1 INDIVIDUAL LEVEL

I have already spoken of the right of individuals who happen to have a disability to make their own decisions and their own choices about how they wish to live, as well as about services they need and how these should be provided. This carries with it the corresponding obligation for human service workers to support individuals in their own choices, rather than to decide on their behalf what is best for them. It also means that services need to be flexible, adaptable, and portable in order to respond to the needs and interests of individuals, rather than forcing clients to fit into the boundaries—or physical settings—of existing programs. It implies that services need to take more of a customer approach in addressing the interests of the client, as determined by the client rather than the service provider.

8.2 POLICY LEVEL

With respect to the development of policy, it is noteworthy that the major legislative and policy advances I have spoken of, as well as most others, have resulted from the advocacy efforts of persons with disabilities themselves. In Canada, people with disabilities, according to Statistics Canada, now constitute some 15% of the population. This is larger than many other interest groups, especially when one adds in family members, friends, associates, and supporters. The disability community is now a significant political force. But this is so only because people with disabilities have asserted their right to be disabled and to live and participate in the community, and because they have not hesitated to associate with other disadvantaged or "devalued" people in the pursuit of a common cause.

For example, rights of people with disabilities were not initially protected in the first draft of Canada's new constitution. In particular, there was initial opposition to providing for the equality of people with mental disabilities. They received this protection only after strong representation by the entire disability consumer community. This would not have happened if people with disabilities had tried to be as invisible as possible. It came about because they were willing to assert themselves and demand their right to participate in society on the same basis as others.

The same phenomenon has also happened elsewhere. For example, the Americans With Disabilities Act resulted from political pressure from people with disabilities and their advocates. Legislative advances in Sweden and Denmark have been a result of advocacy efforts of people with disabilities them-
"SCANDINAVIAN" NORMALIZATION FOR THE 1990s

selves, as well as parent organizations (e.g., Bank-Mikkelsen, 1976b; Billimoria, 1993; Ericsson, 1992; Hollander, 1993). It is also worth noting that the Normalization principle itself was first expressed not by a service professional, but by an advocate, Bengt Nirje, who at the time was ombudsman for the Swedish Association for the Developmentally Disturbed, which, unlike parent associations on this side of the Atlantic, does not operate services and acts solely in an advocacy capacity. It is also not irrelevant that Nirje's background is not in social services, but in the humanities (poetry and comparative literature) and in humanitarian aid (e.g., working with refugees on behalf of the Red Cross and the United Nations).

Professionals and service agencies have been sometimes supportive, and too often strongly opposed, to the above and related policy changes. But for the most part, they have played, at best, a secondary role. It is the people most affected who have played a leadership role in advocating for change.

There is increasing willingness by governments to include people with disabilities in the policy development process. I will provide just one example.

The “Mainstream 1992” federal/provincial-territorial review of services, mentioned earlier, set up a reference group, with representatives of the major national consumer organizations in Canada to provide for consumer participation in the review. (It also used other media to give others input into the review.) Consumer participants appreciated the openness extended to them by the government representatives, for example, by giving them access to all documents as well as the opportunity to meet with senior government officials. A typical comment was: “They actually listened to our and my input with sincere interest and have shown honesty in their efforts to incorporate our feedback.” Reference group members felt that their participation did make a difference. As one person stated, the final report reflected an agreement on vision and philosophy that was different from what either government or the community would have come up with on their own but which both parties could accept.

Members of the reference group were also given the support they said they needed in order to participate fully in the review. For example, a deaf participant was supported in bringing along a sign interpreter, a person with a physical disability had an attendant, and the People First representative, at his request, was permitted to have a supporter of his own choice to help in participating fully in the review.

8.3 PROGRAM LEVEL

The greatest resistance to consumer involvement tends to be at the program or service level. I am founding president of the Advocacy Centre for the Handicapped (ARCH), a Toronto-based legal advocacy centre that carries out test case work and engages in legal and consumer advocacy. Since the center was founded, its bylaws have required that a majority of the members of its board of directors must be consumers. In Ontario, an advocacy commission is being established to provide advocacy services for vulnerable adults. A majority of the commission directors must be consumers. How many social service programs and agencies provide for more than token involvement of consumers in establishing their direction?

The importance of the consumer movement—and Normalization in the 1990s—has important implications for future roles for professionals and for social service agencies. I already have spoken of the need to support individuals in making their own decisions, rather than in doing so on their behalf. But even more profound changes are necessary. The organization and the focus of service agencies and the role of professionals need to change.

For example, segregated, parallel services that remove people from the community are no longer appropriate. The role of social service agencies needs to change away from the provision of direct, segregated services to that of advocate, facilitator, enabler, and supporter in order to help make it possible for people to participate in the community, using regular community services, as much as possible.

Even more profoundly, social service workers and agencies need to act in a new and different way that involves less control over people. This implies a very real transfer of power from the professional to the consumer. It requires a letting go, for example, supporting consumers and community service providers rather than providing services directly and making all the decisions.

It is difficult for agencies to change their mode of operation. And, ironically, as noted earlier, there tends to be more resistance from social service agencies to
A QUARTER-CENTURY OF NORMALIZATION AND SOCIAL ROLE VALORIZATION

independent community living than from many mainstream sectors. But it can—and is—being done. There are good examples of organizations that have succeeded in reorienting and restructuring away from a former model of direct delivery of segregated programs to supporting people in the community. A portion of my consulting work involves working with organizations to help them in changing their roles and strategic direction.

And change is necessary. In the 1990s, consumer control or “empowerment” is more important than anything—including Normalization, Social Role Valorization, or any other theory. It is no longer appropriate for anyone to dictate what they feel is best for labeled people. Any professional service, theory, or approach that does not support the right of consumers to decide for themselves what they want is no longer acceptable nor legitimate. This implies using concepts and language that are simple and understandable to consumers and not steeped in jargon or excessive theory. The overall Normalization field has much to answer for in this regard, and I would hope that its next steps will be to bring its concepts down to earth and make them consumer-centered. And I believe this can be done.

I will go further still. Within a decade, or even sooner, I predict that services that are not consumer-centered and consistent with the priorities of people with disabilities will cease to exist. The newly developing private-sector focus on service and quality—which is now defined by the consumer rather than by the service provider—has yet to hit the public sector. But it will. And when consumers have the right to choose their own service providers and to dictate how services are to be provided, along with the control over funds to make this possible, agencies will be forced to respond to what consumers want—or go out of business. And this is also coming.

What does this have to do with Normalization? As noted earlier, consumer control, empowerment, and self-determination are, and always have been, central to “Scandinavian” Normalization.

9 CONCLUSION

Consumers with disabilities want the right to full inclusion in society—but with their disabilities and their differences. They do not feel that they should have to try to hide their disabilities in order to be accepted and in order to have the same right to participate in the community as anyone else. They want access to power, to determine how they live and the direction of policies and programs that affect them.

The original Normalization principle, as it emerged from Scandinavia is, first and foremost, about rights. It means that society should not turn a disability into a handicap. It means that people—all people—are entitled to whatever support they need in order to participate fully in society.

Normalization means that all people, whether or not they happen to have a disability, have the right to make their own choices about how they live their own lives. This really is a very simple concept. It does not need to be, indeed it should not be, overcomplicated. It is quite in keeping with the demands of the consumer movement. And it is just as relevant now for the 1990s as when the Normalization principle first emerged a quarter-century ago.

REFERENCES


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NOTES

1. See Billimoria (1993) for the most comprehensive review in English of the background in Scandinavia leading up to the formulation of the Normalization principle, as well as a discussion of legislative developments and services in the Scandinavian countries for people with mental handicaps. Also see Nirje (1992) for a personal account of how he came to develop, and later expand upon, the principle.

2. A detailed critique of Wolfensberger’s perspective on rights, conformity, and deviancy, and its implications, is beyond the scope of this paper, but see Bleasdale (in press), the various papers in Brown and Smith (1992a), and Perrin and Nirje (1985).

3. “Employment equity,” which was coined by Abella, is used in Canada in similar ways to which “equal opportunity” or “affirmative action” is used elsewhere.