1 INTRODUCTION

This chapter is concerned with research from Norway and Sweden about persons with developmental impairments and the services they receive. Most research has been related to national reform efforts, particularly in the field of mental retardation, and attempts to evaluate these reforms. Research has, however, not been limited to narrow evaluative questions, but also more fundamental ones about past and present aspirations and patterns, nature of social relations and welfare, and dilemmas in determining appropriate research paradigms, strategies, and criteria for measurement.

Patterns of human service in Norway and Sweden resemble past developments and current trends in many other European countries, as well as in North America. Large-scale, centralized institutions for people with mental retardation were built to a growing extent during the first 6 decades of this century, although at different times and different paces in the two countries. This was an era dominated by containment and control, categorization, centralization, and institutionalization, patterns already in place in countries such as France and England, as well as in the field of mental health in Scandinavia, where state asylums were established in the late 1800s. Initial reform efforts in the 1960s and 1970s were basically aimed at improving the institutional-based system, whereas current trends are in opposite directions: physical and social integration instead of segregation; supports for greater personal autonomy instead of control by others, individualized forms of support instead of categorical and congregative responses; supports in own community settings instead of in institutions; and a decentralization of responsibility and service provision to local levels.

Specific examples include the phasing out of segregated “special” schools to be replaced by supported education within the generic public school system, and the dismantling of long-stay residential institutions to be replaced by supports for participation in one’s own community, including a home of one’s own. Also similar to many other countries, these changes in Norway and Sweden have been most dramatic in the field of mental retardation, with mental health reforms initially evolving more slowly and quietly.

These changes have been accompanied by ideologically charged phrases such as normalization, integration, equality, participation, self-determination, solidarity, and “one society for all.” As official social policy goals these phrases have been important symbolic slogans, more than clear guidelines for practical implementation. Mostly what one has witnessed thus far is a mixed-improvement movement. Living conditions for many individuals and groups previously neglected appear to be improving. More individuals are now participating in a greater variety of activities in their home communities, in roles such as homeowner, classmate, wage-earner, churchgoer, voter, club member. One is also increasingly aware that while physical and organizational integration have vastly improved, many individuals remain socially isolated and feel lonely, and that as improvement in living conditions occurs, new challenges and dilemmas are revealed. All of this requires that researchers...
continually ask new questions, both about the type of questions being asked and the ways that questions can and should be answered.

Normalization and integration have continued to be central social policy objectives in Norway and Sweden for more than 25 years. While lack of clarity and consensus as to the specific content of these ideas has been problematic from an implementation perspective, the same lack of clarity has encouraged debate and analysis, and has contributed to subsequent concept evolution. Social research (sociological, psychological, educational) in both Norway and Sweden has been greatly stimulated by reform effort aimed at these dual goals of normalization and integration. The intention of this chapter is to provide an overview of that research as well as to call attention to some features that are rather unique in an international perspective. One section of this chapter reviews two generations of research about integration, showing how research questions have changed: from a focus on the relation between physical and social integration to questions about the nature of social relationships and everyday life, as well as broader questions about ideologies, their development, and societal role and function. The next section presents some approaches and dilemmas concerning research surveys on living conditions, their relation to the Scandinavian welfare state ideology, as well as some dilemmas in using these surveys as measures. The final section highlights several aspects of the central dilemma: the tension between paternalism and individualism. One might even say that this dilemma is at the heart of debates about the welfare state in general, and in any case is a recurrent dilemma in social policy debates.

Both Norway and Sweden have long been described as model welfare states, and much of what is discussed in this chapter is presented within this context of the Nordic welfare state. If we understand the original meaning of "well-fare" as "traveling well and safely through the journey of life," it becomes something we would wish for ourselves and those we care about. The term welfare has positive connotations in the Nordic countries, compared to its usage in other languages and cultures.

From a distance, Norway and Sweden may appear similar, but there are also many differences, some of which sometimes seem important and enduring. Some of these differences may become more apparent in the future, as Sweden joins the European Union and Norway does not. Although this chapter has as its central focus the circumstances for people with mental retardation in these two countries, the issues and dilemmas raised are intended for a wider readership, both in the interests of other groups at risk of social exclusion and within other societal contexts.

2 FIRST GENERATION OF RESEARCH ON INTEGRATION: WHAT HAPPENS WHEN PEOPLE ARE INTEGRATED?

The integration of persons with mental retardation has been ambitious as a political goal and diffuse as a conceptual vision. Attempts to evaluate the extent to which integration has occurred, and to interpret its results, have reflected this lack of clarity.

In Sweden, two "generations of research" can be identified, the first of which refers to research examining and evaluating the first attempts at integration. Several such projects were started in Sweden in the early 1970s. Some of them studied integration in preschool and school. Others were focused on housing, looking at the results of moving persons from institutions into other types of sheltered accommodation such as group homes. Some "first generation" research is evident in Norway, although primarily in the field of education, encompassing studies about the effects of integrated schools, and primarily carried out by special educators.

The goal of integration contained two basic lines of argument: an ideological or political-ethical one, and an empirical or more instrumental one. Each of these two directions has different implications for research.

The goal of integration, for example, could be argued from an ideological standpoint: that integration in itself is "right" and "good." The institutional service model, in particular, was interpreted as a violation of basic values and rights. Segregation in institutions included control over where one lived, with whom, and under what circumstances. It was seen to violate basic values of freedom, choice, equality, and opportunity. In this perspective, the alternatives to institutions such as "integration" were interpreted as "good" because of accordance with these basic values. Whether to integrate or not is then a political question, or one of societal consensus, rather than a research question. The role of research is not to answer whether this is a right or wrong decision, but rather to describe and measure the progress
of what is already concluded to be "right," to measure the degree to which social policy missions are being implemented.

The second line of argument represents a more strategical or instrumental view: One could also argue that integration is "good" because of its positive effects for the individual person, by promoting personal development. In the field of mental retardation, one asked questions reflecting those assumptions, such as whether a person's self-image improved, whether learning and general adaptive development occurred more rapidly in integrated contexts, and so on. In other words, research questions attempted to describe and analyze whether or not community integration had had positive or negative effects on the individual person's development. From this perspective, integration has to, so to speak, prove itself. Butterfield has called deinstitutionalization and integration "natural experiments" (1987), and the role of research is to answer the question whether life in community has positive or negative effects on different aspects of the individual. Living arrangements are thus seen as independent variables whose effects on the person with mental retardation could and should be scientifically assessed.

Both the ideological and the instrumental dimensions were present in the Scandinavian debate, although the distinction between them was not explicitly stated. From an international perspective, it is probably safe to say that the dominant argument in Scandinavia was ideological in nature: integration as "good in itself." This is also mirrored in the questions asked by early research. Its main focus was on how far the goals of social integration had been reached, not on its effects on personal development. In an international comparison, the absence of research showed one major pattern: Whether in preschool asmervik, 1976), or housing (Soder, 1970; Kebbon et al., 1981), results indicated that the goals of social integration had not been fulfilled. In analyzing this outcome, a distinction was often made between different forms or aspects of integration: physical, functional, social, and societal (Soder, 1970). Physical integration referred to the mere "physical mixing" of disabled with nondisabled persons. Functional integration referred to the extent to which disabled and nondisabled persons were using the same functions and resources in the environment. Social integration referred to social relationships and feelings of belonging with others, regardless of disability. Societal integration referred to the extent to which rights and living conditions were the same for disabled persons as compared to nondisabled persons. Most research indicated that the physical placement of persons with developmental disabilities was to varying degrees connected to functional integration. The dimensions of functional integration could perhaps also be called level of participation. It concerned, for example, the degree to which pupils in school were sharing the same facilities and participating in the same activities as nondisabled pupils, the degree to which persons living in group homes were using generic amenities and facilities in their society (using ordinary buses, shopping in stores, visiting cinemas and theaters). Although the degree of such functional integration, or participation, was shown to vary, it was sometimes concluded that the level was in any case greater than in institutions. At the time, this was not a trivial result, as deinstitutionalization was still a "hot" issue.

The degree of social integration was also shown to vary, although at the lower end of a scale: generally, different studies showed that social relations between the "integrated" person with disabled and nondisabled peers/neighbors were not very frequent or well developed. In some studies of housing integration, social isolation was pointed out as a major problem.

The interpretation and practical conclusions drawn from these findings varied. Some persons argued that physical integration was in itself positive, creating natural learning situations for social and adaptive behavior and, by supporting people with disabilities to be part of the life experience of others, could in the long run help change attitudes and prepare the grounds for social integration. Others maintained that integration was only meaningful to the extent that it meant being socially included, and that physical integration was interpreted only as a first step to that end. Or, as Gustavsson (1992) put it, physical integration meant making society accessible for disabled persons.

Quite another, perhaps more important, question was how the advantages and disadvantages in society should be dealt with (Gustavsson, 1992). One practical conclusion drawn from this perspective argued for greater consciousness among staff, to raise the ambition and conscious purpose from mere physical integration toward social integration, and some projects were developed where ways of working in group homes and schools were
focused as a way of facilitating the accomplishment of that goal.

The first generation of research was thus focused on issues about social relations to nondisabled persons as the indicator of the extent to which the goals had been met. During the 1980s the scope of research interest broadened. One project led by Sonnander and Nilsson-Embro (1984) described and measured life circumstances for groups with impairments, using a number of "quality of life" indicators. As rated by the interviewers, persons with developmental disabilities scored below the mean on a 5-point scale, while populations categorized as nondisabled and those with physical disabilities received higher ratings. The study also showed that developmentally disabled persons had access to more activities than they made use of, and that their social networks were poorly developed and rarely of their own choosing. Interviewers also typically described those interviewed with developmental disabilities as having a negative self-image. Asked about their own satisfaction with different spheres of their lives, however, the majority of those interviewed expressed satisfaction. The only indicator with a positive correlation between assigned (by others) and self-reported ratings was in the area of leisure-time activities.

This project provided new insights and dilemmas, and created what could later be called a "bridge" over to a second (and ongoing) generation of research.

3 SECOND GENERATION OF INTEGRATION RESEARCH: BROADENING THE PERSPECTIVE

Present-day research studies and projects in Sweden more or less grew out of the results of the earlier first generation of research. Present studies in Norway are more the result of increased research allocations earmarked to evaluate the effects of recent reform efforts, including the comprehensive reorganization of mental retardation services.

Three types of research can be distinguished: research on social relations, research on everyday life experiences, and historical studies about development of ideologies and service practices. To a certain extent, each of these areas has its counterpart in international research. A fourth area of research in Norway and Sweden is the use of living conditions surveys as a method to evaluate reforms. This tradition is—as far as we know—unique to Scandinavia, and will therefore be discussed in greater depth in section 4 of this chapter. It should also be noted that the following three-part classification is not intended to be comprehensive, but is rather an attempt to describe major patterns, which then excludes some important contributions. This would include Stangvik's important work in adaptation of the normalization principle (1987) to a local context, and his efforts to make this a practical tool (1994), and an ongoing related study by Kristiansen (1994).

3.1 SOCIAL RELATIONS

The first generation of research led to more basic questions about social relations. How did social relationships become established, especially between disabled persons and their nondisabled peers? What were the social experiences of all concerned? Attention was directed to environmental, interpersonal, and personal factors that invited and facilitated social integration. Gustavsson (1992) has attempted theoretically to identify conditions for the development of social integration, using the classical gemeinschaft and gesellschaft dichotomy (Tönnies, 1963), in order to specify the typical conditions of social relations in modern, urban societies. The conditions for social integration are dependent upon the fact that social relations are to an increasing extent a reflection of personal preference and choice. This "micro-social-pluralism" manifests itself as a growing individualism, where persons with less-valued traits tend to be rejected. Gustavsson argues this as a key to understanding why "integration reforms" have not been as successful as hoped for. They have been built on a rather nostalgic (naive?) view of a stable and tight social network—gemeinschaft—which has little basis in modern societies (Gustavsson, 1992).

This insight does not necessarily mean that integration is impossible, but only more unlikely and/or difficult to achieve. One example that illustrates this is an empirical study of social processes in a housing block in a mid-sized Swedish city. Nilsson (1993) carried out a longitudinal study on this housing block, which had been redesigned to facilitate social integration of older people, as well as those with physical and mental disabilities. Her results describe a waning enthusiasm after the first few years, coupled with small changes—less engagement in the common affairs by nondisabled tenants, greater numbers
of disabled persons being placed there, more structured segregative leisure-time activities offered—all of which tended to accumulate to create what was recognized and described as patterns of segregation. By describing and making these changes visible, and a subject of discussion, the trend was reversed. Today the block is relatively well-functioning in terms of social integration. Nilsson points to three characteristics that have been important to create and maintain this state: conscious physical planning that creates natural informal meeting places, a well-composed range of leisure-time activities capable of integrating all tenants, and the presence of informal voluntary leadership who personally engage themselves in the everyday lives of people living there. With reference to the Tönnies dichotomy, Nilsson characterizes the social life in the block as “Gesellschaft with some distinct features of Gemeinschaft” (p. 158).

These examples illustrate the change in emphasis from evaluative questions about social relations and toward a deeper probing into the nature of social relations, and the nature of segregative as well as integrative societal processes.

3.2 STUDIES OF EVERYDAY LIFE

One criticism of the early integration studies has been that they centered too much on a particular kind of social relation: spontaneous, voluntary friendship relations between disabled and nondisabled persons. Often such freely given, mutually rewarding relationships were seen as the criterion for judging successful social integration, disregarding the fact that other forms of social relationships can be close and rewarding, as well as important facilitators of social integration (see, for example, Tassebro, 1992a). There has been a tendency (albeit often implicit) that relationships with family, staff, or others with impairments are “not social integration.” The question of what constitutes “good social integration” has come increasingly into the spotlight as physical integration of persons with severe impairments has progressed.

There has thus been a growing interest in studying the everyday life experiences of persons with disabilities. These studies are not as much focused on social relationships alone, but attempt to capture the total life experiences of persons before, during, and after the deinstitutionalization process, often using qualitative methods.

One example is a longitudinal ethnographic study of about 30 persons with severe mental retardation moving from an institution to group homes. Anchored in their own experiences, several themes have thus far been identified as critical, such as autonomy and the importance of communication (Jeppsson, 1989). A corresponding example from Norway is a project where 5 persons moving out of institutions are being followed. In addition to an ethnographic descriptive approach, anthropologist Sundet is attempting to identify the social meanings of what is being experienced, including the effect of different kinds of rationales as determinants on the lives of people outside the institution (Sundet, 1993). These studies disclose that personal choice and influence are seen to be severely limited in daily life. This pattern is confirmed by Jarhag’s (1993) study of severely impaired people living in group homes, where programmatic routines leave very few margins for residents to make decisions according to their own preferences. Sundet has described much of this pattern as a “cultural lag”: The routines that dominated institutional life are transferred when the organizational frame is changed (Sundet, 1993). Wuttudal’s recent work expands this in her studies on support workers in residential services, and identifies how the content and cultural meaning of “home” is often “invaded” by the worker’s style of intervention and organizational workplace culture (1994).

Söder, Barron, and Nilsson (1990) studied the life situations of 60 persons with different severe disabilities and identified the following obstacles to personal autonomy and influence: bureaucratic forms of organization, bureaucratic rules, professionalism, and stereotypes. It is worth noting that these obstacles are the same as the general characteristics of the welfare state, which are currently the target of neoliberal criticism. On one hand, if such criticisms are valid, they may be as much, if not more so, for persons with severe impairments who would be more likely to need and/or be dependent on public welfare services. But it also indicates that the interest in autonomy, influence, and self-determination is in alignment with the more general criticism of the welfare state. This could also be interpreted as an extension of “new individualism” into the disability field, as part of a more universal shift away from collectivism and societally defined norms for decency and toward a faith in the individual’s personal freedom of choice and subjective satisfaction.
Compared to other countries, the use of the “quality of life” concept to capture the everyday life situation has been very minimal and attempts to construct standardized measures for quality of life nearly nonexistent, with the exception of the aforementioned study. One reason is the trust in standard-of-living surveys to cover the essential areas, and to do so in ways that are more objective (than subjective) and collective (rather than individualistic). Additionally, the “quality of life” concept has been criticized because of its linkage with discussions on right to treatment, euthanasia, and abortion, as well as in the field of health economics, where concepts such as “quality adjusted remaining lifetime” are used to determine the presumed benefit of services (Söder, 1991; Kirkebæk, 1991; Kristiansen, 1993).

### 3.3 DISCOURSE ANALYSIS OF IDEOLOGY

A third category of the current generation of integration research are attempts to examine ideologies in broader historical and societal contexts. Of special interest are studies seeking to understand the roots of idea systems, such as normalization and integration, in relation to the emergence of the welfare state. One explicit underlying assumption is that one can better understand society, particularly modernization and the development of the welfare state, by identifying the patterns of experience for marginalized groups. Ericsson (1992) has argued that some basic idea of normalization (including use of the term itself) is present in public documents from the 1940s, used by a committee investigating the future direction of labor market training for physically impaired persons. This is one of many signs that normalization has developed continually alongside the Scandinavian welfare ideology, with heightened interest after World War II. Sandvin (1994) has recently begun to study the developments of social policy in terms of phases of differentiation (specialization, categorical segregation) and de-differentiation. De-differentiation and decentralization are tempting trends today in an era when bureaucratic structures are seen as top-heavy and expensive. This is further fueled by the strong belief by some in local social networks, and the hope that generic systems can and will develop the capacity to deal with all kinds of unique “special” problems.

In an attempt to explain past and current ideological shifts, Söder has hypothesized a basic ambivalence in value structures (1992). He describes historical shifts as resulting from a mismatch between ideologies that have evolved from concrete problems, which then become incompatible and unable to resolve the new problems created. When, for example, normalization and integration are formulated as responses to the problem of segregation, they become obsolete constructs in relation to the problems many people with disabilities face today, who have been described (albeit erroneously) as “integrated” and in “normalized” settings.

Discursive historical analysis has grown out of the previously mentioned interest in understanding current thought and practice in a broader sociohistorical perspective. Such research questions may seem quite removed from the original evaluative questions concerning degree and type of integration. But they can also be seen as a natural and more in-depth continuation of the questions and results of “first generation” research in the field, as part of a search to understand why and how integration became an issue in the first place.

### 3.4 NEW REALITY, NEW RESEARCH QUESTIONS

There are several reasons for the shift of emphasis between what have above been referred to as first- and second-generation research, three of which deserve to be mentioned in this context.

First, many would argue that integration has become a relatively noncontroversial issue in Sweden and Norway. The pressure on researchers to evaluate certain conditions in order to legitimate the need for comprehensive reform is no longer as strong as it was in the early 1970s. Debates “for or against” integration are fewer, replaced by questions and challenges about practical strategies and consequences.

Second, earlier-held expectations by some that physical integration would more or less lead to social integration began to wane with increasing attempts to integrate people with more complex and severe disabilities. Instead, comparatively more interest has been given to questions about which forms of social relationships are possible and desirable for severely disabled persons, and also looking more broadly at total life experience.

Third, in the first generation of research in Sweden, researchers were often contracted directly by national boards or a county council, often disconnected from research and academic communities. Today in Sweden
and Norway, there is more conscious effort to foster disability research within centers of academia. This may account for the breadth and depth of the questions being asked, and also may contribute to a greater sensitivity to the "fashion" effects of respective disciplines, since some research developments can be understood as reflecting larger trends within such fields as sociology, anthropology, and psychology.

4 LIVING CONDITIONS AND THE WELFARE STATE

The theme of living conditions has always had a central place in discussions of the welfare state in Scandinavia, both as a main objective of governmental programs and also as a focus for research efforts. This has long been true for the population in general, and more recently also for people with disabilities. When the welfare state is seen to have a role in ensuring better living conditions for certain disadvantaged groups, a number of ideological questions begin to appear. This section is an attempt to highlight and discuss some of these questions and dilemmas, in relation to current research approaches. Questions such as collective responsibility and/or individual choice also lie at the heart of today's most heated debates in human services and critiques of normalization, and thus deserve this lengthier discussion.

4.1 USE OF SURVEYS

Scandinavian research has a long-established tradition of using standardized surveys to monitor the major areas of living conditions, such as housing, occupation, earnings, health, leisure and recreation, social network, and property ownership. In addition to documenting patterns of change in general, a central purpose of these surveys has been to identify and monitor patterns of difference and inequality among populations and groups. These surveys have been providing input into the sociopolitical agenda for over 20 years and are institutionalized in Norway and Sweden as ongoing public sector activities at the national level. Since the 1970s, these surveys have been carried out on samples of the general nondisabled population.

Until recently, however, the use of living conditions surveys to reveal patterns of inadequacy and inequality has been rare within disability research and unheard of in the field of mental retardation. Currently a number of larger-scale, nationally financed evaluations using a living conditions survey approach are under way in both Norway and Sweden, including inter-Nordic comparison (Tøssebro, 1988, 1992a; Kebbon, 1992; Tideman, 1992; Åkerström, 1993).

4.2 BETTER OR GOOD ENOUGH?

The current studies are basically evaluative in nature and purpose, intended to measure current reform efforts and impacts. The first question asked is fairly straightforward: Are living conditions for people with mental retardation improving? This research question suggests use of a pre- and post-test design, comparing living conditions "before" and "after" implementation of a reform. The question of "improvement," however, is somewhat anemic today, since living conditions for mentally retarded people have been gradually improving in Norway and Sweden for the past 25 years, and the new wave of reforms is intended to be something more (or different) than a mere continuation of an existing trajectory.

In Norway, for example, the service system was to be changed because it was judged to be not good enough according to sociopolitical standards. According to a major public committee report, living conditions for people with mental retardation were described as "humanly, socially, and culturally unacceptable" (NOU, 1985, p. 12). This critique demands that researchers ask a different question: not Are living conditions improving?, but rather How much improvement is "good enough" to be deemed acceptable? In order to discern or discuss this, it is necessary to have data for comparison, as in, What is life like for other people of the same age in this locality? The use of the living conditions surveys appears to easily meet this need for comparative data.

4.3 COMPARATIVE STUDIES: WHY NOW?

There is reason to ask why such comparative studies appear now, and also possibly why only in Scandinavia. One simple explanation is that the tradition of living
conditions surveys already exists and is well-established as a public sector function. Second, since one of the major explicitly stated objectives in the present reforms is to improve living conditions, the use of such surveys to assess change is a logical choice of approach, especially given the existence of the method.

At a less obvious level, certain ideas embodied in the Scandinavian welfare state are important in this discussion. In one sense, the welfare state is a package of programs enabling and supporting the basic welfare of its citizenry. But there is another, larger (and somewhat more elusive) idea incorporated in the numerous changes in public sector tasks and responsibilities in many Western countries after World War II. British sociopolitical scientist Marshall called this the emergence of “social citizenship” (1950), whereas recent studies about welfare states frequently use the concept of “decent” (Mohan, 1988; Esping-Andersen, 1990; Bryson, 1992; Mishra, 1990). The underlying belief is that everyone is entitled to decent living conditions, not because of one’s labor-market value, but because of one’s citizenship status. In addition, the decency principle contains a public dimension: the notion of public responsibility that living conditions for all citizens should pass as decent according to collectively agreed upon (but not necessarily explicit) standards.

Further, there is consensus in Scandinavia that general living conditions measures are considered to somehow be indicators of “the good life.” As in other societies, however, one does hear arguments against this such as “different people value different things” or that “the good life is a personal, subjective experience.” Scandinavian sociology provides three counterarguments, each one of which anchors the objective measures in factors important enough to cut through individual/subjective variation, at least in terms of influencing social policy. Briefly, these three strategies are:

1. The consensus-based perspective (Johanssen, 1970), which suggests that while agreement on the good life may be difficult or impossible, most people in a society could probably agree to a reasonable degree what constitutes poor or unacceptable conditions, and that such consensus is sufficient for constructing central elements in social policy.

2. The second strategy has its foundation in resources/exchange theory, which argues that some measures of living conditions, such as earnings, wealth, social resources, and employment, are not ends in themselves, but rather are resources to obtain or achieve what one wants. With reference to social policy, the resources one can mobilize to fulfill one’s choices are more important than the personal tastes involved in actual preferences (NOU, 1976).

3. The needs-based and Maslow-inspired strategy, which argues that certain broad dimensions of welfare are anchored in basic human needs (Allhardt, 1975, 1976).

The point is not whether these strategies are right or not, but rather that all of them (most explicitly the consensus perspective) give great attention to social political relevance. None of the three strategies would define a dissatisfied millionaire worse off (or more eligible for public support) than a poor, homeless, undernourished person who was reporting contentment. The conceptual labyrinth of “the good life” is simplified by a political focus. The issue is not to illuminate or unravel the philosophical complexities of defining the good life, but rather to understand the public duty and responsibility with regard to access to, and distribution of, the good life.

4.4 COMPARATIVE STUDIES: WHY NOT BEFORE?

Given the fact that the use of living conditions surveys in Norway and Sweden have as part of their purpose to uncover social differences as a step in the government’s addressing such inequality, the more interesting and surprising question is not why this approach is appearing now, but rather why the use of living conditions surveys has not been used before for this greatly disadvantaged group of the population.

How can it be that while the decency principle was evolving during the 1950s and 1960s in Scandinavia, and was said to encompass all citizens, as late as 1971 half of the mentally retarded people in long-stay residential services were still sharing rooms, frequently with more than three persons who were often total strangers (NOU, 1973)? Most conceptual discussions and related research on the welfare state, whether national or comparative in scope, focus primarily on the large economic transfer schemes. It is illustrative to note the differences between political debates on retirement benefits and disability pensions on one hand, and services for people with learning impairments on the other. In both cases, the demand has been for increased public expenditure, but in the case of services for people with mental retardation, the
ambition was typically translated initially into the more modest purposes of increasing the number of beds, and prior to the 1960s, discussions about "quality" were nearly nonexistent.

Media-enflamed scandals during the 1960s resulted in changing public opinion and shifts in social policy. In a certain sense, the welfare state was aroused. There were gradual changes for the better with regard to living conditions, but certainly not quantum leaps. In particular, the demarcation between common decency standards and institution-based living conditions continued to be clear. One explanation is that living conditions in an institutional setting have different (unspoken yet "known") criteria than for others in other settings in society.

In the 1980s, there were clear differences between official guidelines for institutional standards in Norway and what was otherwise deemed acceptable for others in society. An example is the institution-based objective that "by 1988 three-quarters of the residents should have their own room of at least eight square meters." Yet according to standards set for generic housing by the Bureau of Statistics, a space of 8m² would be considered overcrowding, and the Norwegian National Housing Bank would reject any loan application from an ordinary citizen on this point alone, as it is in violation of decent housing standards.

The comprehensive reform that has started in Norway as of 1990 has a political rhetoric that may recharg the arguments for common decency standards. Norwegian public committee reports (NOU, 1985) explicitly couple the concept of normalization with acceptable living standards and specifically mention the life domain areas traditionally catalogued in living conditions surveys in their service evaluations. The current reform in Norway has "normalization and improvement of living conditions" as its official purpose (Parliamentary bill Ot.prp.48 [1987-1988]), and in the Parliamentary debate, shortcomings were listed in the areas of employment, income, education, participation in leisure and cultural activities, and so on (statement by member of Parliament, K. Helland). The gap between the publicly sanctioned mandates and actual practice may remain wide. But the political recoupling of welfare state standards to conditions for people with mental retardation both makes it easier to advocate for such normative standards, and makes it reasonable for the fields of research to evaluate current and future changes as an extension of the welfare state to include all citizens, assessing living situations according to cultural norms and "decency criteria." An essential aspect is the altered public perception of people with mental retardation as fellow citizens, flowing in part from the reconceptualization of mental retardation as a social issue rather than a medical one.

4.5 A MIXED LIVING CONDITIONS APPROACH

It may appear from the foregoing discussion that living conditions surveys and decency are closely connected, but this is only partially true. A description and comparison of important life domains is likely to increase the capability to be able to detect and monitor major inequalities and unacceptable conditions, at least when it comes to those variables regularly measured in these surveys. In discussions of living conditions for the general population, many factors are taken for granted and go unmentioned and thus unmeasured in the surveys. Yet many of these factors are factors not necessarily granted to people with mental retardation, and/or are factors that may have great significance in their lives and thus deserve to be considered in the evaluative process, in addition to what the normative surveys will reveal.

For example, living conditions also have meaning: A home is more than a house, and a house is more than a place to stay. In an ethological perspective, one's home is the core private territory, marking off an area where one's privacy is expected to be respected and protected, and where entrance by others is usually invited or at least permitted. This is something so taken for granted that most of us do not consciously think about it, except on occasion of violation. If territoriality is no longer violated (as was previously the common practice in most residential institutions in Norway [Tøssebro, 1992b]), then housing has changed its meaning in a way that is probably important to identify in our quest for decency criteria. Similarly, from a semiotic perspective, housing tells a tacit story, sending out a set of signals to the world about its inhabitants. The large institutions are hugely visible monuments, symbols of societal exclusion and devaluation, sometimes with a dash of danger and mystery. Having a key to one's own front door and an ordinary street address are symbols and images of a new status for many individuals, examples that indicate symbolic elements of "home" that are important to describe and document in a societal reform.
A related challenge is that “decent/good enough living conditions” would also include having one’s individual needs for support and development addressed. Receiving only what others receive may not be appropriate or adequate for an individual with extra needs, which may require something more or different than only what is “normative.”

We would thus suggest that a general living conditions approach is fundamentally sound as a method disability research, but the approach will require a few modifications, a few extra or highlighted variables, that are of special importance to many or most people with disabilities who have historically been politically and socially excluded as a class of people.

5 EPILLOGUE: THE PATERNALISTIC DILEMMA

It should be obvious from the previous sections that social research in the field of disability in Norway and Sweden is rather diverse and pluralistic in its approaches. Quantitative approaches, including use of living conditions surveys, have revealed inadequacies in terms of culturally defined expectations and decency norms. From qualitative studies one gets in-depth glimpses into the experiences of everyday life, which help us better identify with people’s lives, and also may be helpful in our attempts to understand the societal processes that create or maintain deviations from the societal norms of decency.

Each of these perspectives, however, has an explicit or implicit normative dimension to it. The way we describe, interpret, and understand what is real will have implications for how we will act to maintain or change that reality. The tension between a quantitative/objective approach on the one hand and a qualitative/subjective approach on the other hand arises when one begins drawing normative conclusions. The rationale behind use of living standards surveys grew out of a “social-engineering logic,” such that the purpose of the surveys was to provide input for rational decision making, to ameliorate “bad” living conditions and inequalities. This quest for decency—although ideally based on a democratic political process—can also be expressed as something to be implemented in the interests of disadvantaged citizens, whether they want it or not. In contrast to this “paternalistic” approach, a more subjective and individualistic approach is implicit in many of the more qualitative everyday life studies. More specifically, the descriptions in these studies of the powerlessness and subordination of mentally retarded persons calls for more sensitivity in listening and thinking about issues of power and autonomy. Growing struggles for increased self-determination and self-advocacy groups demanding “control over our lives” sharpen the immediacy of this debate.

This paternalistic dilemma is at the root of present more general discussions about the nature and future of the welfare state. It is thus larger than only a question concerning people with disabilities. To put it simply, one can accuse the paternalistic approach of being a well-meaning but oppressive tendency of the state to interfere with what individual citizens say they want or what they can do with their lives. This argument is central to the neoliberal critique of the welfare state, where individual “freedom of choice” is considered a more important aim than politically and collectively determined standards. The subjective/individualistic component is also at the core of many popular conceptualizations of “quality of life,” with claims such as “quality of life has no meaning apart from the experience of individuals” (Taylor & Bogdan, 1990, p. 28). Such sentiments cannot be solved by arguing that certain objective conditions lead to subjective experiences, since studies show no strong relationship between objective and subjective measures (Campbell, Converse, & Rodgers, 1976; Veenhoven, 1984).

In this final section we hope to articulate and discuss this paternalistic dilemma in relation to the research approaches previously discussed. What intensifies this discussion as a dilemma is when individuals or groups choose, or are willing to accept or approve of, conditions that are what others in society would consider unacceptable, indecent, or inadequate when compared to others of the same age in the same society. Since present day “modernistic” thinking tends to favor the individualistic/subjective perspective over collective/objective “paternalism,” we will look most closely at certain problems with the individualistic perspective. We have focused our attention on two central problem types: the use of subjective reports and the issue of respect for individual freedom and preference.
The first years were terrible...30 on a ward. But
today is different, only 6 on a ward, and he has his
own room...There is even a swimming pool. Sad
they're closing it down now, when they are all
having such a good time.

Would she have been as content if her non-disabled
35-year-old son shared a house with 6 others but at
least had his own room? What is her frame of
reference for judging the situation as “good enough”?

2. Contextual adaptation. Human beings are
known to be very adaptive, both psychologically and
physically, in part perhaps as a means of self-
preservation. This also applies to our subjective well-
being. People with incapacitating medical problems
still report satisfaction with life in the same way as
others do, except when they have recently experienced
deterioration (Eriksen, Naess, & Thorsen, 1989). One
man who had lived homeless in London for several
years said, “I got so used to life on the streets that I
often didn’t notice anymore that I was hungry and cold
and smelled badly until after I had come in somewhere
and had a meal and a bath.” It seems that the initial
response to any change in conditions is to become
more (or less) satisfied, but the longer-term response is
to adapt—to change—one’s frame of reference. Such
an interpretation is in keeping with conclusions from
Inglehart’s studies on values (1977) and the quality of
life studies by Campbell, Converse, & Rodgers,
(1976). Others have indirectly substantiated this claim
by adding that longer-term satisfaction (or
disappointment) is better termed a personality
characteristic rather than a response to life conditions.
In any case, if it is true that a person (or group) will
with time adjust to very different situations to the point
of no longer noticing, including conditions initially
experienced by themselves as hurtful or degrading or
unpleasant, then certain reports must be interpreted
from a different frame of reference than only the
reporting person’s own perspective.

3. Identity defense. It appears to be natural to
defend who and what we are, and especially the
identities and roles we know we have. Some months
ago on Norwegian television was a program
interviewing adolescents with cancer. All of the
participants were at the time without symptoms, but
many had uncertain prognoses. Many expressed shock,
anxiety, and practical problems, but also presented an
attitude one could summarize as “I would not have
been deprived of this experience.” In addition to possibly more existential explanations, a partial explanation relative to our discussion is that we all tend to defend our identity, even if (when) that means defending or reporting satisfaction with situations such as a medical setback or very unsatisfactory conditions.

When combined with adaptation processes, one could predict that in the extreme, some persons may be willing to accept very poor conditions, perhaps even expressing not only satisfaction but gratitude. People have been known to “choose” degrading and unsatisfactory conditions, not only because they are known and familiar, but worse, because one has accepted that one does not deserve more or better. At this extreme point, one can talk about internalization of societal devaluation.

5.2 THE SECOND PROBLEM TYPE: RESPECT FOR INDIVIDUAL FREEDOM AND PREFERENCE

Self-determination can be seen as an end in itself, or it can also be regarded primarily as a means. Some interpret self-determination as the right to direct one’s own action to fulfill one’s own preferences. Since the subject is the only person with firsthand knowledge of these preferences, then self-determination is a presupposition for fulfillment. But the right to direct one’s own action does not necessarily concur with the ability to fulfill one’s preferences. Apart from the obvious that not everything we may want will come true no matter what we do (no matter who we are), other prerequisites may also in any case be necessary, such as existence of alternatives, knowledge of alternatives, and supported access to them, and the ability to predict likely consequences of choosing one option or route over another. If such presuppositions are invalid, less externally imposed control would automatically lead to more active control, but not necessarily to more fulfillment of one’s own preferences, in fact, but rather to more mistakes. Would we call this self-determination? In the example of one young Norwegian man with mental retardation living for the first time in his own home, both he and staff were pleased with his new environment, his privacy, and his self-determination. Staff were less proud when they realized that even if he knew how to buy meat or fish for dinner every day, he did not know how to use the stove. Surely it was not his self-determination or preference to choose to eat it raw, as he had for many weeks (Jenssen, 1992). In such instances, arguments for self-determination as end-in-itself or as means-only will lead us in opposite directions.

No one doubts that greater personal autonomy, self-determination, and having more choice and control over one’s life is important. But it is then also essential to remember that most of us have also received support and assistance in learning how to make choices, what to consider, and have some sort of way that we have learned to weigh alternatives and possible consequences. Persons who have been controlled by others up through adult life, and been excluded from ordinary life experiences, often simply do not know how to make decisions. In any case, in situations where self-determination is the dominant aim, and without supports for learning how to make decisions, we end up with examples such as “he wants to sit in the corner and rock all day,” or someone who “decided” to go outside for a walk in the snow wearing only underwear, or someone who destroys their health and teeth by “choosing” to spend all their pocket money on sweets.

Both of the above problem types refer to important conflicting considerations and possible pitfalls. On the one hand, one can argue that individual satisfaction is a better tool of social control than for social policy, since persons living in poor or unacceptable living conditions will tend to adapt or “feel content,” and others may report that “he is content with his lot,” altogether serving to powerfully sanction and maintain the poor conditions. A fierce focus on self-determination can further legitimate staff withdrawal, less public expenditure, and can turn out to be not “dignity of risk,” but rather outright neglect. On the other hand, we ourselves would not use any of the arguments described in the above two problem types to tolerate having our own opinions or self-determination ignored in our own lives. Why then, it is argued, should it be less offensive to ignore the wishes or opinions of a person who, for example, has mental retardation?
This dilemma is very real and as such cannot be easily resolved. As social scientists, however, our task is to be mindful of the possible pitfalls and risks, especially for the most vulnerable groups in our societies. And in everyday life this dilemma needs to be balanced. Such balancing is subject to negotiations and change, and with current trends favoring individualism and more pluralism, the individual may end up being more autonomous but less powerful. Autonomy is gained but at what cost and for whom?

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