

A comparison of living conditions for intellectually disabled people in Norway and Sweden: Present situation and changes following the national reforms in the 1990's

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Abstract: In the 1990's, the service system for intellectually disabled people underwent national reforms in both Norway and Sweden. Responsibility was transferred from county to local authorities and institutions were replaced by community services. This paper presents a study comparing living conditions of intellectually disabled people in the two countries. Both living conditions immediately after the reforms and also the changes taking place during the reform years are compared. The paper is based on data from 987 (pre-reform) and 1183 (post-reform) subjects (born 1922-1970, 47% females). Results suggest fairly similar developments in living conditions, but there are a number of differences as well. In both countries changes in housing conditions are substantial. Changes for people affected by deinstitutionalisation were greater, compared to changes for people affected only by the transfer of responsibility. Results are discussed in relation to similarities and dissimilarities in the history of deinstitutionalisation, reform strategies and legislative foundation of services.

During the last part of the 20th century, deinstitutionalisation became a pervasive trend. This occurred in a number of countries, although mostly in the so-called Western world. Several sectors within the social service system were affected, such as psychiatric services, special education, services for older people, child protection services, services for intellectually disabled people, etc. Even though an overall international trend clearly exists, that does not preclude important dissimilarities across sectors or between countries. Some

countries have closed all institutions for intellectually disabled people, while others have not. Foster homes are the common new option in child protection, but occur rarely in other service sectors, at least in Scandinavia. In some countries community services are private or voluntary, in others public. In short: Neither the institutions, the reform/deinstitutionalisation processes nor the community services were uniform phenomena.

There is an extensive international literature on deinstitutionalisation and

post-institution services. Most of the research is of an evaluative nature, with the main question being whether the services have become better or worse. There is however unexpectedly little comparative research. Certainly, one can find analyses of the overall trends that have an international scope (for example Scull 1984, Cohen 1985) and some accounts of national developments use information from more countries (for example Jones 1993, Sandvin 1996). There also exists a few studies discussing the development in different sectors in one country (for example Sandvin & Söder 1998), and some edited books have contributions from different countries but without being comparative in any strict sense (for instance Mansell & Ericsson 1996, Tøssebro, Gustavsson & Dyrendahl 1996, Flynn & Lemay 1999). From this body of research there exists important information about national similarities and dissimilarities. However, studies that explicitly compare the same variables in different countries or different service sectors are few and seem to be limited to simple comparisons of rates of deinstitutionalisation, usually comparing the proportion of the population living in a specific type of institutions (Hatton et al. 1995, Ericsson & Mansell 1996) or the proportion of children not attending a regular class (Pijl & Meijer 1991). The tradition of comparative welfare state research does not appear to have been incorporated into research on deinstitutionalisation and post-institution services.

This paper will however be a small contribution to such comparative research. We will compare and discuss services and living conditions in two countries that are typically seen as similar: Norway and Sweden. However, in the sector our analyses are confined to, services for adult intellectually disabled people, the two countries do have fairly different histories. The reform strategies and the legislative foundations differ as well (see next section).

The paper is based on the "living conditions approach" (see methods section), and will mainly be descriptive. The intention is not to test any specific hypothesis but to describe and compare the circumstances for intellectually disabled people. The focus will partly (1) be on the post-reform living conditions in the two countries, and partly (2) on changes taking place during the reform years. The situation and changes will be discussed both for people that were discharged from institutions, and for people without a history of institutionalisation. The possible differences in living conditions between the countries will be discussed and related to similarities and dissimilarities in the history of deinstitutionalisation and reform strategies in the two countries. Thus a brief presentation of this history:

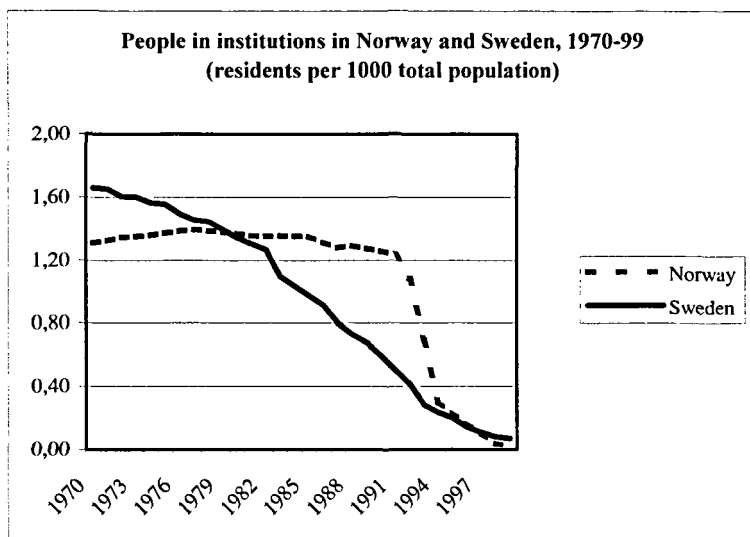
An outline of the history of deinstitutionalisation and reform strategies in Norway and Sweden

The critique of institutions arose in both Norway and Sweden in the 1960's,

and normalisation and integration became central guiding stars in both countries. The strategies and consequences were however dissimilar. In Sweden, a reduction in number of people in institutions started about 1970, and alternative services gradually emerged. During the 1970s the total number of people in institutions was reduced by about 15%. After 1980 the pace of deinstitutionalisation accelerated, and the institutionalised population was reduced by 50 % between 1980 and 1989.

In Norway the total number of people in institutions grew rapidly in the 1960s, levelled off around 1970, and peaked in 1976. From 1976 the institutionalised population was fairly

stable until 1988/ 89. The main strategy in Norway in the 1970's was to normalise institutions, and thus important changes took place inside the institutions during these years. They grew smaller, less centralised, more village-type (many small houses on the institution grounds) and the admittance of children ended. In the 1980s, alternative community services emerged slowly, but did not affect the number in institutions (cf. Tøssebro 1992). The differing strategies between the two countries are well illustrated by the number of people per capita in institutions for intellectually disabled people from 1970-1999 (cf. Figure 1).



The administrative structure of the earlier services was somewhat different in the two countries. In both cases county authorities were running the institutions. However, in Sweden the same county authority was also in charge of community services. In Norway community services was the responsibility of local authorities (municipalities). It is not clear if this made any difference, but a Norwegian public committee report (NOU 1985) argued that one reason for the late onset of deinstitutionalisation in Norway was the financial disincentives on the part of local authorities, and that this was due to the double administrative structure. The point was that if local authorities did not establish community services, the institutions could not discharge residents and the counties would thus have to assume the costs.

In Norway, full-scale deinstitutionalisation took place during a few years in the 1990s. In 1988 the parliament decided to close all institutions, and the implementation was to take place from 1991 to 1995. Simultaneously, the responsibility for services was transferred from county to local authorities. The reform was thus top-down, and a simultaneous deinstitutionalisation and administrative decentralisation. The decision led to a rapid exodus from institutions from 1990 to 1994, more slowly after 1994, and by 1999 nearly all institution residents were resettled in the community.

In Sweden there was no such close link between "administrative decentralisation" and deinstitutionalisation. In

1985 a new Act on care services maintained that county authorities were responsible for services, but a transfer to local authorities could be negotiated between local and county authorities. In some counties one agreed to implement this transfer, but in most no change occurred. The 1985 Act also maintained that group homes/ community services should be the typical future residential option, and that no more people should be admitted to institutions (unless very exceptional circumstances existed). And in fact, the bulk of deinstitutionalisation took place within the county governmental structures. In the mid 1990s, the transfer of responsibility became mandatory in Sweden as well. In 1996 responsibility for services for intellectually disabled people was transferred to local authorities, and it was also decided to close all institutions by the turn of the century.

By the end of the 1990s, the administrative structure of the service systems in the two countries was fairly similar, and the number of people in institutions was close to zero. However, there continues to be some important differences in the legislation regulating the services. The bottom line in both countries is Acts on social services of a so-called framework type. These Acts specify the type of services each municipality is required to have, but they do not grant people individual rights. In order to strengthen the legal position of intellectually disabled people, the Swedish parliament has enacted an additional law that grants

this individual right to intellectually disabled people. Thus, the legal backing of claims for services is stronger in Sweden than in Norway.

To sum up, there are at least three important differences between the countries. First, in Sweden deinstitutionalisation was a more gradual development, whereas in Norway one set up the new system and new services in relatively few years. Second, in Norway the reform was a simultaneous administrative decentralisation and deinstitutionalisation. In Sweden those two changes were mostly independent. And third, the legal backing of claims for services is stronger in Sweden.

There are a number of possible hypotheses and questions that could be discussed or defended based on these dissimilarities. For example "There is likely to be more variation in the Swedish services since they are established during a much longer period" or "Changes in Norway are likely to be more pervasive since the reform is one of both decentralisation and deinstitutionalisation". Our study is however not designed to test such specific hypotheses, but rather to describe living conditions. The paper will have an inductive profile, an empirical description, and then a discussion and interpretation of findings. However, one of the issues that are important to raise, given the dissimilarities in the pace of deinstitutionalisation, concerns the relative importance of deinstitutionalisation and decentralisation. Thus, the descriptions and analyses of changes during the reform years will be done separately for

people who were in institutions before the reforms and people who received community services at that time.

Methods

A wide range of service and subject characteristics has been discussed in research on services for adult intellectually disabled people, such as changes in the adaptive and challenging behaviour of the subject (cf. Larson & Lakin 1989 for an overview), staff-resident interaction and care style (for example Felce et al. 1986) and community presence. Recently a number of Quality of Life scales have been introduced (cf. Hughes et al. 1995), among others one supported by the American Association on Mental Retardation (Schalock 1996). In Norway and Sweden the research on services for intellectually disabled people in the 1990s had a somewhat different profile, one argued the case of the level of living/living conditions approach (Tøssebro 1992, Tideman 1992, Kebbon et al. 1992, Hjelmqvist & Kebbon 1998). This approach has a three-decade history in studies of the general population (cf. Fritzell & Lundberg 1994). The purposes are to uncover social problems, to compare the situation of different social groups and to describe the development of living conditions over time. Methodologically the studies employ nation-wide surveys, and the typical questions are of a descriptive nature on issues such as housing, occupation, income, possessions, health, cultural/ leisure activities, education, etc.

One of the reasons for using this approach in research on intellectually disabled people is linked to the political and ideological underpinning of the reforms. The major purpose was to improve the living conditions, and in so doing to reduce the differences between the typical population and people with intellectual disabilities. In a way normalisation was interpreted to mean a more typical level of living, and could thus be analysed by means of the typical living conditions surveys (for further discussion, see Tideman 2000). The potential of a living conditions approach in research on intellectually disabled people, and the problems and necessary adaptations (including the use of proxy respondents and descriptive measurements), are more fully discussed in Tøssebro (1998).

Subjects and data collection

The data were collected as a part of evaluations of the reforms in the two countries. The evaluations were independent of each other, but data gathering was partly co-ordinated between the countries. Some differences in design and procedures do however exist. The age-inclusion criterion was initially not identical between the countries, but in order to facilitate comparison, subjects older than or younger than the inclusion criterion in any data set were excluded (subjects borne before 1922 or after 1970). An advocate/semi-guardian or the subjects themselves gave consent to the participation in the study.

In Sweden, data were collected by

posted questionnaires in 1991 and 1995. These questionnaires were sent to the population of adult intellectually disabled people in of Sweden's 22 counties, Halland and Jämtland. Both counties were implementing an early voluntary transition to local responsibility for services (January 1991). In 1995, 602 persons responded to the questionnaire (response rate 64 %). None were living in institutions. Among these 602 subjects, 476 had also participated in the pre-reform study in 1991 (the overall response rate in 1991 was 82 %). 110 subjects were living in institutions in 1991. 3% of the subjects answered the questionnaire without help. The other subjects were supported by staff (80%) or by family. Analysis of respondents vs. non-respondents did not reveal any special problems (cf. Tideman 2000).

In Norway, data were collected through structured interviews with residential staff. Subjects were selected by two different procedures. The first group consisted of intellectually disabled people living in residential institutions in three (out of a total of 19) counties in 1989. The study included 591 persons in 1989 (response rate 76%). In the Norwegian data sets, no new subjects were included after the initial sample in 1989. From 1989 to 1994 the number of subjects decreased to 550, mostly due to deaths. However, when data were collected in 1994, not all subjects had yet left the institution. Only subjects who were resettled in 1994 were included in the database of this paper (N=396).

The second Norwegian group consisted of people not living in institutions in 1989 in 53 (out of the total of 436) municipalities scattered around the country. This study included 716 persons (response rate 52%) in 1991 and 641 (response rate 48%) in 1994. In this group, many were still living with their family, and most of them were children. Only subjects born 1922-1970 who received residential services in 1994 were included in the database of this article (N=185). Analysis of respondents vs. non-respondents did not reveal any special problems (cf. Tøssebro 1996), but the low response rate suggests cautious interpretations with regard to the second Norwegian data set.

Our analysis includes two types of comparison. First, a cross-country comparison. This is done only on the post-

reform data sets (the 1994/ 1995 data). Second, the description of changes within each country. This is based on differences between pre-reform data (1989/1991) and post-reform data (1994/1995). The total number of subjects included in the cross-country comparison was 1183 (Sweden N=602, Norway N=581), whereas the number included in the longitudinal comparisons was 987 (Sweden N=476, N=511). The smaller number of Swedish subjects in the longitudinal analysis is because this analysis only includes subjects where both pre- and post-reform data are available. The smaller number of Norwegian subjects is due to the fact that 70 subjects were living with their families in 1991, and a living conditions comparison is thus less relevant for this group. Some characteristics of the subjects are shown in Table 1.

Table 1: Resident descriptors in Sweden and Norway. 1994/1995 data. Percentages. N=1183

	Sweden	Norway
Gender (% female)	45	50 (ns)
Age in 1995 (mean)	45	43*
History of institutionalisation (% yes)	73	77 (ns)
Adaptive behaviour summary scale (mean)	2,59	2,66 (ns)
Items in the adaptive behaviour scale:		
Non-verbal or few words/gestures	39	35
Comprehends some words/ short sentences or less	17	23
Reads	34	31
Writes	31	27
Does not need assistance at meals	63	62
Does not need assistance with bodily hygiene	36	36
Knows how to tell the time	39	37
Can use public transport to familiar places	28	42
Needs 24-hrs assistance	36	36

ns = country difference not significant

* p=.02

The differences in design and procedures between the Swedish and Norwegian study suggest cautious interpretations and conclusions, but on the other hand we see few reasons to expect the differences to be of any vital importance. The variables used in this article are not that responsive to minor design variations, and the subjects included appear fairly comparable (cf. Table 1).

Measurements – country comparisons

We gathered data on several aspects of the subjects' living conditions. In this paper, we compare the results on variables that are identical or similar in the Norwegian and Swedish 1994/ 95 data sets. By similar we mean data where response alternatives were different, but which could be regrouped into the same categories. Only the "regrouped" version of the variables is described below. We will discuss variables concerning accommodation, occupation, leisure activities and self-determination¹. The following variables were included:

Type of housing: Four categories: 1) individual apartment (not in group), 2) apartment in group home (each person has an individual apartment in a house with two to five similar apartments. There may or may not be communal rooms in the house), 3) traditional group home (each person has a private room in an apartment for several people), and 4) institution type accommodation (including homes/ hospitals for elderly people).

House type: Two categories: houses that were of housing-project/many-apartments type and houses of the detached, semi-detached or row-house type.

Private territory markers: An additive index including questions on the presence of a private letterbox, nameplate on the door, and whether the subject has a key him/herself. The index is intended to measure to what extent the housing is marked as personal or private. It is a rough indicator, but it measures nevertheless whether people/staff find it worthwhile to mark the territory as private (index mean 2.2, SD 1.0).

Domestic possessions: Respondents were asked if the subject owned a number of things that normally are present in a household, thus being an indicator of private living. The 7 items were radio, television, stereo, telephone, kitchen equipment, furniture and bed linen. The items were added into a composite measure of number of possessions owned by the subject (index mean 5.8, SD 1.6)

Type of occupation: This variable distinguishes between ordinary work/ workplace; sheltered work; day centres; education; retirement, and no occupation.

Working hours: Number of working hours per day, four response alternatives (1-2 hours, 3-4 hours, 5-6 hours, 7-8 hours).

Non-disabled work-mates: "Do the subject have any work-mates without disabilities, disregarding supervisors and similar"? (response categories yes/no) (The question was supposed to be an indicator of integration at work.)

Poverty: Respondents were asked if subjects during the last year had to renounce because he/ she could not afford it: a) buying necessary clothes, b) going to the cinema or a sports event, or c) going on holiday (replication of a poverty study by Stjernø (1985)). There were three response categories, "frequently", "sometimes" and "never". Variables were added into a composite measure with nine categories (index mean 8.5, SD 1.1).

Leisure activities: Respondents were asked how frequently the subject took part in 14 different leisure activities during the last 12 months. Four categories: 1 – not at all, 2 – a few times a year, 3 – a few times a month, 4 – weekly or more. The scores for all activities were added into a composite measure (index mean 26.6, SD 5.2).

Self-determination: Scale based on 6 questions: what influence did the subject have on: where to live, control of money, participation in decisions on leisure activities, clothing, furniture, and a global question on self-determination in everyday life. The questions had 3 to 5 response alternatives (scale $\alpha=0.89$; mean 16.0, SD 5.2; missing values replaced

by variable mean).

The primary independent variable was country. A number of control variables were considered included in the analyses: sex, age, the subjects' history of institutionalisation (yes or no), and adaptive behaviour (a composite measure of the nine adaptive behaviour variables listed in Table 1. Number of response categories varied from three to five, scale $\alpha=.90$).

Analyses and data presentation

Within the limited space available for a journal article, it is impossible to present a detailed analysis of all relevant variations in the living conditions for people with intellectual disabilities in the two countries. Our choice has been not to single out one or two life domains for a detailed analysis, but to present data in a very condensed fashion and to omit most of the information not strictly relevant to a cross-country comparison. As shown in Table 1, the only suggested control variable with a significant correlation with country is age ($p=.02$), but this correlation is indeed weak ($r=.07$). Thus, the control variables are unlikely to affect the analyses of country differences and are therefore not reported. This implies that the differences between the countries can be fully described in the format of cross-tabulations. Such tabulations have the advantage of not only measuring the variation between countries, but also presenting comprehensible descriptions of the current living conditions for

intellectually disabled people (for instance, the percentage of individuals with a non-disabled work-mate).

Measurements – analysis of national longitudinal changes

In general, the same measurements are employed in the analyses of national changes over time as in the cross-country comparisons. However, because the pre-reform data were not identical with the post-reform data in all details, some minor adjustments were done. The adjustments are described in footnotes.

Post-reform living conditions in Norway and Sweden: Cross-country comparisons

A summary of the results from the cross-country comparison is shown in Table 2. The typical Type of housing in both Norway and Sweden in the mid-1990s was the “new style” group homes; group homes where each person had his/ her own apartment, with sitting-room, bathroom, kitchen, and bedroom. There may or may not be communal rooms. There were usually 2-5 individual apartments in such group homes. This “new style” group homes were even more typical in Norway. 67% of the subjects in Norway lived in such houses, compared to 58% in Sweden. Individual apartments (not parts of group-homes) were slightly

more common in Sweden (cf. Table 2). In the two countries, about the same proportion lived in “old style” group-homes (where the subject does not have an apartment, only a private room; 11%). Institution-like settings were uncommon in both countries.

The differences between the countries when it comes to Private territory markers are minor but significant, slightly in favour of Norway (cf. Table 2). More than 50% in both countries have all three markers, whereas 73% (Sweden) and 83% (Norway) have two markers or more. Furthermore, Table 2 suggests that detached, semi-detached and row houses (as opposed to housing-projects/many-apartments-houses) are clearly more common in Norway.

Table 2: Country differences. Means, percentages. N=976-1183

	Norway	Sweden	
Housing:			
Individual apartment (%)	19	24	p<.05*
Apartment in group home (%)	67	58	p<.01**
House type: detached, row or similar (%)	52	26	p<.01
All three markers of private territory (%)	59	52	p<.01
Occupation:			
Occupation at typical work-place (%)	13	11	ns
Occupation at day centre (%)	40	70	p<.01**
Occupied less than 4.5 hours a day (%)	33	12	p<.01
Has a work-mate without disabilities (%)	22	29	p<.05
Domestic possessions scale (mean)	6.1	5.5	p<.01
Poverty scale (mean)	8.7	8.3	p<.01
Leisure activities scale (mean)	26.0	27.1	p<.01
Self-determination:			
composite measure (mean)	15.7	16.3	p<.05
took no part in decisions on furniture (%)	31	22	p<.01
took no part in decisions on where to live (%)	48	46	ns

* p values applies to tables where the original variables are regrouped into dummy variables with the category shown in the table being one of the categories of the dummy.

** p values apply to the complete tables with the *Type of housing / Type of occupation* variables

ns = not significant

Our data show a rather mixed picture when it comes to occupation, most likely reflecting the different formal structure of occupation arrangements and support services in the two countries. One important difference was that a single system to a much larger extent served everyone in Sweden. 76% were admitted to day centres, 5% worked in the open market and 8% in sheltered workshops. The rest were retired. In Norway, there was more variation. More people were working at ordinary workplaces (13%) and at sheltered workshops (34%), but there were also people with no work at

all (5%) or only a few hours education each week (6%). However, of the 76% admitted to day centres in Sweden, 6% attended at typical workplaces. This implies that a total of 11% were occupied at typical workplaces in Sweden. Thus the cross-country difference in proportion at typical workplaces became insignificant (cf. Table 2)

This picture of a slightly less segregated occupational system in Norway was not reflected in the number of people with a non-disabled work-mate (supervisors excluded). More people were actually working

with non-disabled work-mates in Sweden. Intellectually disabled people in Sweden also tended to work more hours per week.

The results concerning the measures on Domestic possessions and on Poverty suggested an overall similarity slanting slightly in favour of Norway. 77% in Norway and 63% in Sweden had 6 or more of the 7 possessions listed in our questionnaire. A total of 80% did not report restrictions in activities due to poverty in any of the three areas asked for (Norway 85%, Sweden 74%). The differences between the means on both variables are significant (cf. Table 2), but minor.

Intellectually disabled people appear to take part slightly more often in Leisure activities in Sweden - compared to Norway. However, even Norwegian subjects do not differ much from the general Norwegian population (cf. Tøssebro 1996: 156-157).

The mean score on the global Self-determination measure suggests slightly more self-determination in Sweden. In Table 2, we have also presented the percentage of subjects who had no say at all in decisions concerning furniture and in decisions concerning where to live. These are shown as examples of variables included in the not easily interpretable composite scale. In general, it appears as if participation in decisions concerning daily life was fairly frequent in both countries in the mid-1990s, whereas participation in decisions of a more far-reaching nature was less common.

Changes following the reforms in the early 1990s – Norway

The results of the analysis of changes taking place during the reform years in Norway are presented separately for people relocated from institutions and for people who were living in the community (but not with their families) before the reform.

For the people living in the community before the reform, services were mostly provided by the local authorities, but at that time there was not actually an established system for such services. The changes in living conditions for this group can thus neither be linked to the deinstitutionalisation nor to the transfer of responsibility to local authorities. The changes should rather be interpreted as "riding on the bandwagon" of a national reform with a strong ideological superstructure.

A summary of the results for people living in the community prior to the reform is presented in Table 3. The general impression is that the changes were minor or moderate. All but one of the statistically significant changes concern housing. Somewhat more people got their own individual apartment, housing is slightly more marked as a private territory, residential space is somewhat larger, and the subjects tend to have some more private Domestic possessions. The sole significant change that was not about housing was that the mean number of Working hours per week was slightly reduced (26.7 to 24.8 hours).

Table 3: Changes during the reform years in Norway. People neither institutionalised nor living with family in 1989 (N=121) ¹

	pre-reform	post-reform
Housing:		
Individual apartment (%)	41	50**
Apartment in group home (%)	45	41'
House type: detached, row or similar (%)	52	52'
Size of housing (mean square meters)	47	52*
All three markers of private territory (%)	66	77**
Occupation:		
Occupation at a typical work-place (%)	14	17'
Occupation at day centre (%)	13	17'
Has work-mates without disabilities (%)	27	29'
Working hours (mean per week)	26.7	24.8*
Domestic possessions scale (means)	5.9	6.5**
Poverty scale (means)	8.4	8.6 '
Revised leisure activities scale (means)	19.8	19.6'
Revised self-determination scale (means)	9.7	10.0'

* p<.05 ** p<.01 ' not significant

Table 4 shows the results for people who left the institutions between 1989 and 1994. Even for this group the general impression is that the reform was mainly a housing reform, but in this case the changes in housing conditions were substantial. The earlier Type of housing – living units in institutions where each person had a private room – was replaced by group homes where each person had his or her own apartment. Thus the number of persons with two rooms (cf. footnote 2, Table 4) or more saw a sevenfold increase and the average size of private space increased four times. The number of Domestic possessions also showed a substantial increase, and more Private territory markers were present. Data not shown here confirm the picture of clearly more private and homelike living (Tøssebro, 1996: 97ff). One should

also note that fewer people live in detached, semi-detached or row houses after the reform. This reflects a change from the “village-type” institution where most units were of a semi-detached kind.

When it comes to life domains other than housing, most changes were significant but moderate. The Type of occupation did not change much. There was, however, a reduction in the number of people receiving adult education (from 25 to 7 %, cf. Tøssebro, 1996: 108). Furthermore, there was an increase in the average number of Working hours per week. Changes as measured by the Poverty, the Leisure activities and the Self-determination scales were minor or moderate. One should note that the changes in Leisure activities (cf. Table 4) mean that people were engaged in fewer activities after the reform.

Table 4: Changes during the reform years in Norway. People institutionalised in 1989 (N=390)^{II}

	pre-reform	post-reform
Housing:		
Individual apartment (%)	3	6'
Two private rooms or more (%)	12	81**
House type: detached, row or similar (%)	71	53**
Name on doorplate (%)	11	37**
Size of housing (private sq. m. mean)	13	48**
Occupation:		
Occupation at typical work-place (%)	5	6'
Occupation at day centre (%)	50	56'
Working hours (mean per week)	17.8	24.1**
Domestic possessions scale (means)	2.9	5.9**
Poverty scale (means)	8,5	8,7**
Revised leisure activity scale (means) ^{III}	25.6	23.5**
Revised self-determination scale (means)	5.2	6.3**

* p<.05 ** p<.01 ' not significant

Changes following the reforms in the early 1990s – Sweden

The results of the analyses of changes taking place in Sweden are also presented separately for people relocated from institutions and for people who were living in the community before the reform (and not living with their families). Prior to the reform, the counties had the responsibility for support and services. Through administrative decentralisation this was subsequently transferred to local government. Thus for one group the changes was a decentralisation reform, whereas for the other group it was simultaneously decentralisation and deinstitutionalisation.

Table 5 presents results for the group of intellectually disabled people who were living in the community in 1991 (N=366). As in Norway, the main

impression is that the changes that took place were relatively moderate. The most evident changes concerned housing. More people lived in "new style" group homes, their own apartment, after the reform. More people were also living in detached or row houses; they scored higher on the Private territory markers measure, and had access to more Domestic possessions. Scores on the Leisure activities scale were somewhat reduced, whereas the number of Working hours per week and the scores on the Self-determination scale increased.

Table 5: Changes during the reform years in Sweden: People neither institutionalised nor living with family in 1991 (N= 366)^{IV}

	pre-reform	post-reform
Individual apartment (%)	17	21'
Apartment in group home (%)	31	58**
House type: detached, row or similar (%)	22	35**
All three markers of private territory (%)	61	75**
Occupation at a typical work-place (%)	10	7'
Occupation at day centre (%)	69	66'
Has work-mates without disabilities (%)	26	32'
Working hours: less than 4,5 hours a day (%)	14,8	9,8*
Domestic possessions scale (means)	4,0	4,5**
Revised leisure activities scale (means)	31,9	30,6*
Revised self-determination scale (means)	11,7	13,2**

* p<.05 ** p<.01 ' not significant

Table 6 shows results for intellectually disabled who moved out of the institutions during the years 1991-1995 (N=110). Even for this group the main changes concern accommodation. As a consequence of the gradual dismantling of the institutions, the number of individuals with their own apartment, individual or in a group home, has increased considerably. More individuals

also live in houses of detached/row type and with all the three Private territory markers present. There is also an increase in the private possession of objects taken into account on the Domestic possessions scale. A minor reduction in Leisure activities has taken place, but at the same time, the number of Working hours has increased, which is also the case for Self-determination.

Table 6: Changes during the reform years in Sweden: People institutionalised in 1991 (N= 110)^V

	pre-reform	post-reform
Independent apartment (%)	0	3*
Apartment in group home (%)	0	89**
House type: detached, row or similar (%)	3	28**
All three markers of private territory (%)	24	58**
Occupation at a typical work-place (%)	0	2'
Occupation at day centre (%)	77	72'
Has work-mates without disabilities (%)	7	7'
Working-hours: less than 4,5 hours a day (%)	20,7	17,1*
Domestic possessions scale (means)	4,4	5,7**
Revised leisure activities scale (means)	29,5	27,6**
Revised self-determination scale (means)	8,2	10,4**

* p<.05 ** p<.01 ' not significant

Discussion

The main purpose of this study was to make a comparison between two countries of the living conditions for adults with intellectual disabilities. Our results show that there are statistically significant differences between Norway and Sweden on most of our living conditions measures. However, most of the differences are minor. Furthermore, the overall impression is that the distribution of differences is not systematic, being sometimes in favour of Norway and sometimes of Sweden, in a more or less random pattern. We see no reason to analyse or discuss further why there are for example more Private territory markers in Norway, and more Leisure activity in Sweden.

There are however a couple of differences that may be more important. One is that it appears as if the housing is more uniform in Norway. The typical “new style” group-home with apartments for each person is even more typical in Norway. This type of group-home is especially frequent among people who left the institutions in the early 1990s – in both countries. Thus, this “new style” of group-home may be interpreted as the model of the early 1990s in both countries, but since deinstitutionalisation has a longer history in Sweden, the typical model of the 1990s will not dominate the overall picture to the same extent as in Norway. The clearly more frequent use of apartments in housing projects in Sweden is also worth noting, partly

reflecting national differences in housing structure, but also suggesting less frequent use of purpose-build group-homes (which tend to be of a semi-detached or row house type).

The more uniform character of the Norwegian system should however not be exaggerated, for two reasons. One is that the differences are moderate. The other is that although housing is more uniform in Norway, when it comes to occupation the results suggest that the service system is more uniform in Sweden. 76% attended day centres (even though a few of the individuals were actually placed outside the centre). In Norway one sees more variation, for better and for worse. More people work at sheltered workshops or at typical workplaces, and at the same time more people were completely unoccupied.

However, the similarities between the countries may be more important than the differences. Both countries have seen the diffusion and dominance of a new type of group homes – group homes where each person has his/her own apartment with a bedroom, kitchen, sitting room, bathroom etc. For people who left institutions in the 1990s, this led to a major improvement in living conditions. For people not living in institutions by the beginning of the last decade, one can observe the same trend, but it is less pronounced. Apart from housing conditions, the changes are minor or moderate in both countries. Typically, people work longer hours and score higher on the Self-determination scale after the

reforms, but on the other hand the participation in Leisure activities is slightly reduced. One can see about the same developments in both countries according to all these variables. It may appear as if the fairly similar ideological and political climate in the two countries is cutting across differences in legislation and history, and produces results that from a living conditions approach appear similar. Other approaches may of course produce different results.

The political reforms in both countries are partly a transfer of responsibility from county to local government, and partly deinstitutionalisation. It would be very interesting, if possible, to separate the consequences of these two dimensions of the reforms. There does not, to our knowledge, exist any method that can achieve such a separation. Actually, one should be very cautious with the whole language and logic of causality when describing changes taking place during a reform. There are so many complex events happening, ideologically, economically, etc., and a number of detailed regulations are changed. But, with this reservation in mind, our findings suggest that the deinstitutionalisation part is much more important than the transfer of responsibility, at least in the shorter run. Living conditions, most notably housing conditions, have clearly changed more for the people who experienced deinstitutionalisation.

For people not in institutions by the beginning of the 1990s, the changes appear slightly stronger in Sweden than

in Norway (cf. Table 3 and 5). This may be interpreted as an effect of the administrative decentralisation (since this does not apply to Norwegian subjects living outside institutions before the reform). It could however equally well be seen as a consequence of the more gradual deinstitutionalisation in Sweden compared to Norway. In Sweden one had an established system of community services in 1990, based on a model for such services developed during the 1980's. In Norway one did not really have an established model, although the generic system served a few mildly intellectually disabled people. The Swedish "1980's-model-of-community-services" appears to be more different from the typical model of the 1990s than the Norwegian "1980's-generic-exceptions". The living conditions of this Norwegian group changed less by being on the bandwagon of the Norwegian reform, than community services in Sweden changed in the 1990s for people who left institutions in the 1970s and 1980s.

The main difference in the legal-administrative structure of services in the two countries today concerns legislation. In Sweden people with intellectual disabilities have more individual rights. The argument for the Swedish legislation is among others to provide a stronger legal foundation for creating acceptable or fair living conditions. Based on the data of this article, however, one cannot see any definite effects of the Swedish rights legislation. The differences across

countries are moderate and unsystematic, and can hardly be attributed to differences in legislation.

Does this mean that rights legislation makes no difference? Such a question cannot have a single or simple answer. The impact of rights legislation obviously depends on the concrete situation, and there may be several reasons why few differences appear in our data. One is that stronger rights may be more important for people applying for services than for people who have passed the threshold and are already being provided with services. Waiting lists may for example be longer – and a more frustrating experience – in Norway. Such issues are not addressed in this paper. Our conclusions only apply to differences in living conditions for people receiving services. Another reason for the seemingly lack of impact of rights legislation is that it is counteracted by other measures. One possibility is that the earmarked economic transfers that occurred in Norway during the reform period nullified the effects of a “weaker” legislation. Another possibility is that the lack of sanctions in the Swedish rights legislations undermines the differences between rights and framework legislations (Hollander 1998, Åström 1998, Lewin 1998). Thus, in order to answer questions concerning the impact of legislation, there is a need for comparative studies with a research design different from this study.

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Endnotes

- ¹ Unfortunately, our questions concerning social relations, health and some other areas were not similar enough to justify a cross-country comparison.

Table 3

¹ Three adjustments are made to the variables described in the measurements section: 1) a variable on the number of square meters at private disposal in the house is included (not present in Swedish data), 2) the leisure activities asked for in 1990 were partly different from in 1994/95. The *Revised leisure activities scale* consists thus of 11 items identical in the pre- and post-reform surveys in Norway, and 3) the item “participation in decisions on where to live” did not have the same meaning before and after the reform, and was omitted from the *Self-determination scale*. The question on decisions on leisure activities was not identical in the two years, and was also omitted.

Table 4

- ^{II} The adjustments of variables described in footnote 1 (cf. Table 3) also apply to Table 4. In addition the item “apartment in group home” is replaced by “having two private rooms or more” because the question of apartment in group-homes was not included in the pre-reform data. More than one room is a proxy for apartment.
- ^{III} 12 items, partly identical with adjustments described in footnote 1 (Table 3)

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Table 5

^{iv} The revised leisure activities scale consists of 14 items identical in 1991 and 1995 surveys in Sweden. Two items about reading books and journals were not identical in the two years and were omitted. The revised self-determination scale includes a item about possibility to decide about the daily life. The response alternatives were dissimilar in the data sets, but regrouped into 5 levels of self-determination.

Table 6

^v The adjustments of variables described in footnote 4 (cf. Table 5) also apply to Table 6.

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