

BOOKS REVIEWS

An evaluation of the deinstitutionalization of persons with developmental disabilities in Norway.

Tor Jenssen

Thesis, University of Oslo, 1996.

Evaluating a reform ?

Social reforms are results of political actions. They represent operationalisations of defined ideologies and are as such influenced by the society and the historic period in which they are implemented. For the last three decades or more the change in ideologies and patterns of services for persons with intellectual disabilities can be summarised as follows "institutions bad - community good". This is an example of a simple, but strong normative guideline, not uncommon in the field of social policy and social politics. To scrutinise and critically analyse the implementation of social reforms and the consequences they have for the everyday lives of individuals is an important, but difficult and hazardous, task.

In 1991 a social reform concerning persons with intellectual disabilities was implemented in Norway. The reform comprised a total dismantling of institutions and a simultaneous transfer of responsibility for services to local (municipal) authorities. The explicit purpose of the reform was to normalise and improve the living conditions of persons with intellectual disabilities, to enhance an independent and active being in company with others, and to close the institutions. The dismantling of the institutions was completed in 1995.

In 1996 Tor Jenssen presented a thesis for the doctor's degree titled *An Evaluation of the Deinstitutionalization of Persons with Developmental Disabilities in Norway* in which he aimed to elucidate the impact of the reform on the lives of individuals concerned. The thesis comprised five reports and a summary. The questions asked

were whether the reform had entailed improved living conditions and improved welfare for the persons studied, whether there were changes in adaptive or maladaptive skills among persons living in institutions and persons living in non-institutional settings and whether the deinstitutionalisation and the process of normalising the living conditions were successful.

The empirical material comprised sixty-four persons (children and adults) with moderate to severe intellectual disabilities, who together with case managers, were prospectively followed during the reform period. The data collected were a selection of behaviours videotaped in structured situations at fixed intervals. Further, the persons studied were assessed by structured assessment scales and inventories. Interviews with staff was also part of the empirical material collected.

Multiple measurements in a quasi-experimental pre-post design yielded the possibility for the author to study and compare changes in adaptive and maladaptive behaviour (including challenging or self-injurious behaviour) prior to the reform and after the move to a more integrated housing (deinstitutionalisation). In a first step, persons in the study group moved out of the institution and half of the group had to wait their turn. Thus, it was also possible to conduct a comparative analysis between an intervention group and a comparison group. Data were analysed on group level and in three case studies.

In short summary, the studies showed that the persons who had moved out from the institution during the period studied had gained better living conditions (housing). However, significant improvement in the behaviours studied was not found. The results showed a deterioration in adaptive behaviour during the initial phase of the implementation of the reform, i. e. while waiting to move out of the institutional setting. In the intervention group, i.e. those who were the first to move, the deterioration in behaviour was stopped after the transition to the new housing. On the other hand, the behaviour deteriorated further among those persons who remained in the institution. The change in maladaptive behaviour was reverse, i. e. while waiting to move out from the institution the amount of maladaptive behaviour decreased and increased later in the new housing. This increase was significant in the comparison group, but did not reach statistical significance in the intervention group (who moved first). The results also showed that staff turnover during the time period studied was high (86 %). The number of staff with adequate training decreased as did access to staff counselling. The results showed a relationship between an increase in adaptive behaviour and staff training. Specially trained nurses (vernepleiere) and staff with no formal training, but extensive experience of working with persons with disabilities, were capable of improving

adaptive behaviour. The study also showed a weak relationship between staff's assessments of behaviour and observed adaptive behaviour. The assessments of staff were more positive regarding individual improvement than what the videotaped sessions of elicited adaptive behaviour showed.

Tor Jenssen concluded that an approaching change in pattern of services and a tight time schedule influenced behaviour negatively; a process that could be difficult to redirect later after the transition into the new pattern of services. He pointed at the risk of the reform being reduced to "just a housing reform".

The objective of the thesis is deinstitutionalisation, i.e. persons with disabilities moving from a sheltered institutional setting into what is called integrated housing and a life in the community. As the dismantling of institutions in Norway together with decentralisation of services for persons with intellectual disabilities was an important part of a social reform the thesis also claims to evaluate the effects of the reform. The study belongs with those numerous studies of community integration or community care, which have been conducted during the last twenty years.

Integration as concept and phenomena emanates from the critique that was directed towards traditional institutions. Integration is defined in terms of all those things that were denied persons with disabilities within the institution.

Researchers on integration choose different approaches. According to Söder (1993), the two main perspectives are the *effect approach* and the *normative approach*. Other designations are *discipline versus policy*, *social science versus civil rights* and *research versus advocate*. The difference in approach is due to how the institution is viewed. The critique of institutions from an effect approach deals mainly with that the institution does not promote personal development. The main research object is then to find out whether the new integrated community setting in a better way can promote what the institutional setting fails to do. In research with a normative approach, on the other hand, segregation in general and institutions in particular are examples of violations of human rights and human values. Examples of dependent variables in normative studies are equality, freedom, and self determination. An important aim is to look for good examples, critical factors and necessary prerequisites for creating favourable living conditions for persons with intellectual disabilities.

Tor Jenssen's thesis is an example of a study that takes an effect approach. Integration has been evaluated and the new housing is under trial to see if it is better or at least not worse than the alternative; the institution. Research on

integration with an effect approach is abundant. Housing is generally treated as the independent variable the effect of which is studied in a selection of dependent variables. The most common dependent variable used, at least in earlier studies, like in Jenssen's thesis has been adaptive behaviour. Results are contradictory due to crude measures and the lack of consensus on the definition of adaptive behaviour. Later studies using activity in daily life as a dependent variable have shown that an integrated housing often promotes a more active life.

During the 1980's research abandoned simple personal characteristics such as adaptive behaviour as they were considered too limited as dependent variables to grasp adaptation to a new environment. The focus of research then shifted towards the effect of integration on the total, objective as well as subjectively experienced, life situation.

More recently, the difficulty in comparing integrated living to living in an institution has been highlighted. The two settings are simply too different. Some researchers have thus abandoned the simple dichotomisation of living conditions and chosen to study how individuals or groups can interact with the environment.

In summary, research using an effect approach has not convincingly showed whether integration is good or bad. The overall results could be that "it depends". It depends on the individuals concerned as well as the environments or settings studied. It has however been confirmed under which circumstances the behaviours of individuals are influenced. Concepts like social participation and social vulnerability and the ecology of support grew out of these more recent studies.

In spite of the fact that Tore Jenssen's thesis adopted a design more or less abandoned in current research, it has merits. The five articles that form the empirical base for discussion and conclusion have been consistently planned and designed, where several important aspects are described. A series of systematic structured studies present a possibility to prospectively follow individual behavioural changes during a radical change of pattern of services for persons with intellectual disabilities. Some valuable knowledge of what takes place during the implementation of a reform or a change is gained. The need of further support and services for persons in integrated settings is also highlighted.

On the other hand, the study design, what the author claims to have measured and especially the conclusions, that are drawn from the data obtained can be seriously questioned. The following critique will mainly deal with the choice of the independent and dependent variables. The selection of variables as well as the

selection of individuals studied was originally done for another purpose, namely a staff training programme carried out within an institutional setting mainly including persons with a moderate or severe intellectual disability. Behavioural change across time was studied in a single subject design. As the adaptive behaviours (individually chosen) overall did not increase, stabilised after a period of time in the new housing, but did not regain its pre-reform level, the author concluded that the reform did not offer the necessary conditions for persons with intellectual disabilities to lead an independent and active being in company with others.

It was found that unskilled and inexperienced staff could not elicit adaptive behaviour as well as more skilled and experienced staff could. This result was interpreted in terms of a high staff turnover and a diminished access to staff training and counselling, which is referred to as an effect of the reform. As a lack of skilled staff apparently was evident before the reform and a high staff turnover rarely is a built-in characteristic of a reform such a conclusion is far too sweeping. An alternative interpretation is that treatment effects were not (yet) generalised across settings and situations, a treatment goal that all behavioural interventions share. Within the group of persons studied there was in fact a smaller group of persons whose behaviour along with the implementation- of the reform actually changed in a positive direction. The characteristics of this small group would have been of particular interest from a normative point of view.

Further, the outcome that staff assessments or ratings were more favourable than what the videotaped sessions showed could be discussed in terms of validity of the dependent measures used. There are several similar examples where alternative interpretations should have been discussed.

The empirical data presented in the study explicitly deals with one aspect of the reform, that is deinstitutionalisation or rather change of housing, but the conclusions drawn are general and not critically discussed. The most important question is then whether it is feasible to evaluate a far-reaching social reform using a selection of limited behavioural variables observed in a limited group of persons and during what in a reform perspective must be considered a limited period of time. Even in straight-forward applied treatment research the independent or treatment variable is a complex package of variables rather than indicators of apparently unidimensional constructs. And finally, can a social reform ever be a variable of choice when looking for an independent variable ?

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Literature:

Söder, Mårten (1993) Community integration: On the importance of asking the right questions. In Johans Tveit Sandvin & Aase Frostad Fasting (Eds.) Intellectual Disability Research. Nordic Contributions. Proceedings of the Ninth Congress of the International Association for the Scientific Study of Mental Deficiency. Nordland Research Institute, NF-report No. 16/1993

By Karin Sonnander

Når omsorgen oppleves krenkede (When Care is experienced as a Violation).

Britt Lillestø

Thesis, University of Tromsø, 1997.

The target group for Britt Lillestø's research is physically disabled adults. She has interviewed sixteen informants but focuses her analysis on seven of them. Britt Lillestø has as a starting point in a social-constructivist and relationist perspective. With reference to Mårten Söder she emphasizes that sociological research about persons with disabilities must have as its point of departure the relationship between disabled people and their surroundings, and that it is important to consider how the disability is being interpreted and understood by others. Her research focuses on: *"How the injury or flaw is seen and interpreted by the parties in the relationship, and how the users see themselves being treated by the staff"*. The method used is phenomenological. With a phenomenological starting point she strives to *"describe, interpret and critically analyze human life and experience"*. There is a special focus on the life histories of five informants.

These life histories demonstrate the difficulties of being disabled, and the dependent situation in which it places the informants. The informants are all disabled from birth, and for this reason the headlines: *"When the Body Sets Limits; "Change in (Life) Perspective", "When Everyday Life is Seen as a Struggle; "Experience of Lesser Worth; "Under the Yoke of the Role of Patient", "Schism and Ambivalence"; "Adjustment to the Career of Being Disabled"* give a clear indication of how these informants experience ordinary, everyday life.

Britt Lillestø's searchlight is focused on the duality of care, *"It is through studies of the opposite of good assistance, i.e. the violation, that good care can be developed and refined"*. The informants assist her in getting insight into when and how care is experienced as a violation. The relationship of dependency between the caregiver and the recipient of care is the central issue. The focus is – with a theoretical starting point in the Danish philosopher Løgstrup – on the personal integrity of people and the accompanying zone of inviolability. Lillestø differentiates between four different aspects of the zone of inviolability, which are important for maintaining personal integrity. They are *"the home", "the body", "time" and "the personal space"*.

It would have been of value if Britt Lillestø had spent more time on a discussion of the concept of care as it is a central part of her project, but this critique does not overshadow the very important insights – which can be generalized – produced by her research.

As far as I can see, the most important result of her thesis is the categorization of the violations, which I feel is of general value. Themes such as "*Hospitalization and Violation of Home*"; "*Violation of the Body*"; "*Violation of Time*" and "*Violation of the Personal Integrity*" reach far beyond the circle of people referred to in the thesis.

The violations are expressed with both despair and anger at relinquishing authority and the users' experience of asymmetry and powerlessness in the relationship. Both forms of violations experienced offer an insight, which can give food for thought for caregivers.

Lillestø's point is that a clinical-medical perspective is not sufficient to handle the often complex and multifaceted problems, which many of the users have – whether they are of a medical, social or psychical character. The caregiver must, from a relationist perspective, think about his/her own role in the relationship caregiver/recipient of care.

The thesis will be of great importance for everybody working within the educational, social or health sector.

By Birgit Kirkebæk