

BOOK REVIEWS

From Institutional Life to Community Participation. Ideas and Realities Concerning Support to Persons with Intellectual Disability.

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Acta Universitatis Upsaliensis.

Uppsala Studies in Education. Uppsala: 2002

Consequences of deinstitutionalization is an area that has been extensively investigated during the last decades. Much of that research has been triggered by the debate about institutions: are they good or bad; can community alternatives live up to the expectations and promises that the proponents foreshadowed? At least in the first wave of research, this seems to have been the most common research question. The answer given has very often been "it depends". The outcome depends on the design of the community alternative, characteristics of the disabled persons, characteristics of the staff, in what kind of community environment integration took place and so on. In this first wave, research was also to a large extent focused on behavioural characteristics of the disabled person (most notably "adaptive behavior") as the measure of outcome.

Later research has gone beyond the simple evaluative question of whether community integration is good or bad and more often focused on the normative question about what a good life in community should look like and how that is to be accomplished. In that perspective outcome measures like "community participation" and "quality of life" have substituted for the more traditional ones. This development in research can be seen to mirror the fact that deinstitutionalization is no longer an issue for political and scientific debate that calls for objective evaluation, but has been accepted to the extent that the basic question is not whether to integrate persons with disabilities into community, but rather how this can best be done.

In Sweden evaluations of deinstitutionalization started in the 1970's, with the MR (Mental Retardation) – group led by psychologist Lars Kebbom in the most active and productive research milieu. Having started with follow up studies of persons leaving a special hospital for criminal offenders with intellectual disabilities, the

group in the 70's started evaluating the recent transformation from institutional services to community based ones. One of the researchers in the group was Kent Ericsson, who ever since has been doing research focusing on the transformation of services, its historical background, its ideological base and its practical results in terms of what it has meant for the everyday life of persons with intellectual disabilities. He has now summarized his research in a dissertation: *From Institutional Life to Community Participation. Ideas and Realities Concerning Support to Persons with Intellectual Disability*. (Acta Universitatis Upsaliensis. Uppsala Studies in Education. Uppsala: 2002).

The focus of the dissertation is a number of studies about the dismantling of Carlslund, an institution just north of Stockholm. Carlslund was founded as an institution back in beginning of the 20th century. In the beginning of the 1950's it was rebuilt and reorganized according to the "pavillon system". It was at the time presented as the best example of what the ongoing modernization of institutions could mean and came to serve as a prototype for many other institutions in Sweden that were built in the 1960s and 70s. But Carlslund's role as a leading model continued, as it was the first of the big institutions in Sweden to be closed down. The political decision to do so was taken in the middle of the 1970's.

Kent Ericsson has been following the closure of Carlslund and the main part of his dissertation is based on the studies he did in the 1980's, supplemented by a series of studies following the development of community services in the 1990's in the county of Skaraborg in the southwest part of Sweden. The rather long time span over which these studies have been carried out also mirrors the development, described above, of research in general. While the earliest studies were aimed at answering questions about whether community alternative was at all possible, later studies focused on the consequences in terms of community participation while the studies from the 1990's take on the subjective experience of persons involved (staff, parents, and persons with intellectual disabilities).

The general perspective in which these studies are placed focuses on the ideological and political background of deinstitutionalization, where the role of the welfare state and its transformations are emphasized. The roots of deinstitutionalization are sought back to after the Second World War years, when the foundation of the modern welfare state was laid. As early as in the late 1940's a parliamentary committee analyzing the situation for disabled people in the labour market formulated a principle of normalization, meaning that no separate measures should be undertaken on the grounds of disability, but that disabled persons problems should be dealt with by the general labor market services. With a twenty-year delay, this principle became the ideological leading star also for the services for persons with intellectual disabilities and deinstitutionalization can thus be seen as the result of the expansion of welfare state values about equality and citizenship rights into this sector. That expansion also meant a break with the long tradition of institutional care. Ericsson talks about two competing traditions in the field. On the one hand there is the institutional tradition emerging in the late 19th century with a clinical perspective, and on the other hand a community tradition with a

citizen perspective. Deinstitutionalization has meant a break with the former and the development of the latter.

The dissertation is structured around three research questions: why residential institutions are closed down, what forms of community based alternatives are needed, and do these alternatives facilitate intellectually disabled persons' community participation.

The answer to the first question is sought in the development of society in general and the welfare state in particular as well as the ideological development within the services for persons with intellectual disabilities. This is manifested in a will to promote a better life for persons with intellectual disabilities, the substitution of the clinical perspective with a citizen perspective, an economic interest of reducing the costs generated by raising standards within the segregated services and a growing awareness of community services as a realistic alternative.

The second question is highlighted by a follow up study of persons leaving the Carlsund institution. The main conclusion is that community based alternatives were developed and that these alternatives serve as platforms for further development of community participation. It is, though, underlined that this is an ongoing process and the importance of the context in terms of political as well as professional support is emphasized.

The third question, whether community alternatives also mean community participation, is answered by a series of empirical studies, cross sectional comparisons as well as longitudinal ones. Four dimensions of community participation are investigated: housing and day activities as a platform for community participation, the personal character of everyday services, participation in the local community and quality of life. These dimensions are measured in a structured way by collecting information from staff and parents. In summarizing the results Ericsson concludes that community alternatives do form a platform for participation. The extent to which this platform is actually used to develop participation varies between the studies and between different areas of participation. Participation in local community, for example, is higher than participation in terms of quality of life. It also seems that the platform provided by integrated housing is more effective in generating participation than daily activities. It is also noted that activities that are initiated at the central level are more effective in creating participation than the ones that emanate from the local level.

The dissertation provides a systematic and well-documented insight into the arguments, problems and results of the early deinstitutionalization phase in Sweden. In pointing out the close connection between general welfare state developments and developments in the field of intellectual disability, Ericsson not only broadens the scope for understanding deinstitutionalization analytically, but also makes a normative point about the importance of breaking the clinical tradition in favor of a citizen perspective that emphasizes the importance of community participation.

It is a pity though that Ericsson does not relate his findings to the rich literature on deinstitutionalization that has been produced during the last ten or fifteen years, thereby missing an opportunity to validate his findings. It would also have been interesting to relate his approach and concepts to later developments in research. It is possible - not least in Scandinavia - to argue that the clinical perspective that earlier dominated research in this field has been substituted by a "citizen perceptive" by using other measures to capture the living situation of persons with intellectual disabilities. Measures of standard of living, which use indicators that makes comparisons with other citizens possible, is one example, another is the growing number of studies focusing on "influence", "co-determination" and "empowerment". It would have been interesting if Ericsson had positioned himself in relation to this development. Is for example "participation" as judged by others a relevant measure of "standard of living"? How should "participation" be understood in relation to "empowerment"? Can "participation", and its sub-dimension "quality of life" be understood as paternalistic remains of the clinical perspective, which other Scandinavian researchers have abandoned?

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Rättssociologiska studier inom området autism. Rättsanvändning i en kunskapskonkurrerande miljö.

(A socio-legal study within the area of autism – the use of law in an environment of knowledge rivalry).

Annika Pfannenstill

Lund Studies in Sociology of Law, 13. Lund: 2002

Ever since Kanner in the 1940's diagnosed "infantile autism", the question of causes, meaning and treatment of persons with that diagnosis has been a matter of controversy. Perhaps more so than ever during the 1990's, when a psychodynamic perspective, that had dominated previous decades, was challenged by a neuropsychiatric one. In the former autism was seen as resulting from early childhood experiences, most notably a symbiotic relation to the mother, and psychotherapy was believed to be the relevant treatment. In the neuropsychiatric perspective, biological factors, like genes and brain damage, were postulated as the causes of autism. It was not seen as curable, but it was emphasized that secondary problems could to a large extent be avoided if the person with the diagnosis was systematically related to in a structured environment. Pedagogy more than therapy was the recommendation.

This conflict between the two perspectives forms the basis for a dissertation in the sociology of law by Annika Pfannenstill: *Rättssociologiska studier inom området autism. Rättsanvändning i en kunskapskonkurrerande miljö.* (A socio-legal study within the area of autism – the use of law in an environment of knowledge rivalry). Lund Studies in Sociology of Law, 13. Lund: 2002. The ambition is to describe how persons with autism have been dealt within the caring sector and analyze the use of laws in that context. She focuses on the development during the 1990's, the time when the conflict between the two perspectives became obvious.

The data consist of six cases, that is individuals who have been diagnosed as autistic or as having autism-like conditions. One of the cases is a pilotcase, both in the sense that it has been given much attention in Swedish media and in the sense that Pfannenstill started her empirical analysis with this case. The woman constituting this case has spent more than 30 years in psychiatric care. She has spent several periods in institutions sometimes against her will and been the object of physical force ("tvångsåtgärder"). The other five cases have been recruited through self selection. Through the journal of the National association on Autism parents that recognized themselves and their own story in the pilotcase were asked to participate in the study. The six persons thus selected are in the age range of 20-46; four men and two women. All of them have a history of complicated behavioural problems, they have been subjected to several different diagnoses (e.g. schizophrenia, psychosis, multiple personality, symbiotic psychosis) and different forms of treatment, but today they have a neuropsychiatric diagnosis. All cases also show a history of different opinions about causes, diagnoses and treatment

among professionals, conflicts between professionals and parents, and parents who have been highly motivated in fighting for better treatment of their children.

By going through medical journals and legal documents Pfannenstill reconstructs the cases to make them comparable and tangible for a theoretical analysis. The reconstructions are structured as chronological case stories with particular emphasis on the treatment and diagnosis and the intervention of legal, monitoring instances (like the National Board of Social Welfare – Socialstyrelsen - and the Board for monitoring professional practice – Ansvarsnämnden). All the cases have been the object of such interventions and the analysis focuses on how relevant laws have been interpreted and applied.

In sketching the legal background, the author shows how social rights for persons with disabilities in Sweden have developed from laws, where counties were obliged to provide services, to a law from the middle of the 1990's where persons with certain disabilities are guaranteed concrete forms of services, and where these rights can be claimed by appeals to higher courts . This development is also understood as a development where the regulation of civil rights is supplemented by the development of social rights, where the ambition is not only to protect citizens from violations from the state, but to address problems of distribution of power and economic resources. Such regulations of social rights can be of different kinds, depending on which kind of rationality they are based on. Some laws (like in Sweden "lagen om Psykiatrisk tvångsvård" and "Lagen om rättspsykiatrarisk vård") are based on "rationality of norms", where the law itself allows rather small margins of freedom for those who are applying it. The normative premises are built into the law and applying it is a more or less formal procedure. Another type of rationality is the instrumental goal-means rationality. Laws built on this type of rationality stipulate which goals should be attained, it leaves the questions of means to those who have to apply the law (In Sweden the law on Health care – Hälso och sjukvårdslagen – is an example of this). In this situation applying the law calls for more than just knowledge about rule application. Professional substantial knowledge is needed to be able to predict which means will help reach the goals.

In relating her results to the discussion of different forms of laws and rationality, Pfannenstill makes the point that the Act on support and services to persons with certain disabilities (LSS) do give persons with autism a privileged position in terms of rights to specific types of services. On the other hand, though, the civil servant applying the law also needs to be knowledgeable about the specific characteristics and circumstances concerning persons with this diagnosis. Given the contradictive perspectives in the field this places the civil servant in a difficult position between competing interpretations from professionals

The maltreatment and controversies about diagnosis that are so evident in her case studies can be seen as scientific controversy that scientists and professional are unable to solve themselves, with detrimental consequences for the persons concerned. In her concluding discussion Pfannenstill looks for alternative ways of overcoming the kind of passivity and status quo that is the result of applying the law in a field dominated by knowledge rivalry. Using Habermas' distinction

between the system world and the life world, her interpretation is that the law and the legal system tends to be dependent on system-knowledge, based as it is on professional scientific knowledge. The life world and the knowledge generated by the experiences of disabled persons and their close relatives, have great difficulties in reaching into the legal decision making system. At best, the legal system offers a kind of psychological outlet, but not a change with regard to the concrete living situations for persons with autism, nor indeed helping to solve their problems. Rather than a legal system that is made defensive and passive by scientific controversies, Pfannenstill calls for a system that is capable of breaking loose from such controversies and base its decisions on concrete experiences of the life world.

The cases presented provide a dramatic and upsetting picture of shortcomings of professionals and failures of the psychiatric care system as well as insights into the constant struggle of parents and how they are torn between hope and despair. The strength of the dissertation is the systematic reconstruction of these cases and the way they are put into a broader picture of scientific controversy and developments in the sociology of law.

However, the analysis (the two final chapters) is rather thin and as a reader I find myself cheated on an analysis about the interaction between (different kinds of) laws, professionals' knowledge and the role of civil servants in applying the law. Pfannenstill describes the development of "social rights laws" (as the Swedish LSS) as a big step forward in safeguarding the rights of persons with autism, although a description with some inherent problems. Her discussion about what kind of knowledge is needed in different kind of legal systems could have benefited from a distinction between professional knowledge (possessed by legitimized professional groups like medical doctors or psychologists) and the kind of knowledge possessed by civil servants or street level bureaucrats. The rights law does not eliminate the importance of the former kind of knowledge, but changes the balance between the two. This has consequences for the person with a disability applying for services. Being eligible means having a professional assessment that certifies that you are among those groups of "persons with certain disabilities" to which the law applies. Professional assessments, typically a medical diagnosis, are not possible to appeal. It is supposed be based on scientific knowledge and qualified experience on behalf of the professional. It is possible to get a second opinion or to get a board of experts to review the diagnosis, but not to appeal on the basis that rules have been applied in the wrong way. The latter though is the case with judgements made by street level bureaucrats. One of the basic ideas with the law is thus to supply the client with a legal way of exerting influence. But that influence does not include the ability to contradict professional diagnosis. I think the dissertation could have benefited from including this discussion, in particular as some of the cases presented can be interpreted as good examples of this dilemma.

Another problem is that Pfannenstill at the same time as she recognizes the controversial nature of professional perspectives in this area, seems to be quite confident that the neuropsychiatric perspective is the scientifically valid one. It is not a good point of departure for an analysis of controversies to be convinced that one side is right and the other wrong. Instead, the usual strategy for such an

analysis is stressing the importance of treating both sides the same way. But Pfannestill gives priority to the neuropsychological perspective in both her description of what autism is (that is solely built on references to proponents of that perspective) and in her reconstruction of the cases (where a neopsychiatric diagnosis is seen as “relevant”, “realization of the basic problem”, “true description of the causes of the problem”). This also puts the concluding discussion about system knowledge as opposed to life world knowledge in a peculiar perspective, as it seems to be based on the idea that the neuropsychiatric perspective (the one that is shared by all the struggling parents) becomes the knowledge of the life world, rather than representing the professional knowledge on which the system-knowledge is based.

But taking a normative stand in a controversy is, of course, nothing wrong in itself. The problem is that it is done under the guise of being open, inductive and heuristic. I think the whole analysis would have benefited from a clear declaration in the beginning of the dissertation that the author adheres to the neuropsychological perspective. The aim of the project could then have been to analyse why that perspective, in spite of its scientific and parental acceptance does not get implemented in practice and what role the legal system plays in that process.

Despite these critical remarks, the quality of the very informative empirical and descriptive parts of this dissertation makes it easy for me to recommend it to anyone with a special interest in either autism as such, sociology of law applied to social politics, or indeed both.

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