BOOK REVIEWS

Shaping Justice – Defining the disability benefit category in Swedish social policy.

Author: Marianne Hedlund
Lund dissertations in Sociology 58, 2004.

The categorising of individuals plays an important role in the provision of social rights. Its function is to separate those entitled to welfare provisions from those who do not have such rights. The formation of such processes is an interesting phenomenon for sociologists to study. Marianne Hedlund argues in her thesis that we need more knowledge of this field. Her ambition is to deepen our knowledge of the social processes that constitute the disability category in welfare policies, which in turn determine if and what kind of welfare provisions are to be delivered. More precisely, her aim is to review a) criteria and definitions used to construct disability as a social category for social security provisions in Sweden; b) boundaries and principles that are drawn to demarcate disability legally as a social category for welfare provisions and; c) to explore the underlying concepts used to define such disability categories. It is not the implementation *per se* of such definitions and criteria that are focused upon, nor the different views of social actors on such aspects, but what is presented as evidence and requirements for being categorised as disabled. Here, Hedlund makes a distinction between Criteria for Legislated Disability Categories, C-LDS, that are formal and legal criteria – and Criteria for Non-Legislated Disability Categories, C-NDC, i.e., the public's conception of the phenomenon of disability. The idea is that there is a mutual interdependence between them; the one affects the other.

The thesis uses a social constructionist perspective; it is an in-depth study, a case study based on primarily secondary sources such as legal texts, public investigations and official documents and guidelines.

Theoretically and conceptually, the discussions in the thesis with regard to categorisation are based on several sociological classics. Simmel's notion of ”social types” and his relational concepts, ”the stranger” and ”the poor”, are used to explore the formation of a disability category. Durkheim's and Mauss' notion of categories as social belief systems expressing socially constructed symbolic meanings, are thought to fulfil integrative functions in our differentiated society, since such meanings are related to legal definitions and social welfare laws. Other sources of inspiration are Foucault, who links categorisation processes to power structures and D. Stone, who claims that the disability category became vital to the welfare state for the purpose of managing a distributional dilemma, namely to separate those in need of welfare provision from those who could work. Hedlund also reviews welfare state researchers like T.H. Marshall, Offe and Esping-Andersen in order to give a social policy context for the C-LDC.

The empirical portion of the thesis contains a synchronic analysis, i.e., an examination of different social security regulations for one year, 1995. The idea is to analyse the C-LDC of such programs in one and the same historical context. The other part of the empirical analysis is a diachronic analysis for the period of 1958-1985 of one disability payment program (handikappersättning) and its forerunners, for the purpose of exploring the basis for the appearance of its' specified legal criteria.

The synchronic analysis reveals a pattern of three disability discourses that each represent distinct ways of categorising disability: disability as a) rehabilitation potential, i.e., work incapacity as a temporary condition that can be eliminated by means of (vocational) rehabilitation measures; b) economic liability, i.e., economic compensation for loss of income due to sickness or disability or compensation for extra care or costs of living, and; c) disability as a disturbance in everyday life, i.e., social services and support to facilitate autonomy and self-determination. It is concluded that, among all of the various social security programs, the disability program is the one that is justified by all three discourses.

I am not sure if the discourses are as distinct as Hedlund claims. The rehabilitation discourse initially appears to be rather clear-cut, but it certainly also contains elements of economic liability, i.e., compensation for loss of income which begins after one waiting day and continues until the person is granted a disability pension. The economic liability discourse also seems to be intertwined with a caring discourse, since parents are being supported economically to take care of their children or to facilitate a combination of paid work and parenting.

The diachronic analysis shows that the development of the disability program, in contrast to its forerunners (vårdtillägg, blindhetsersättning, hjälplöshetstillägg) depends less on medically defined concepts of disability. Notions of work ability and social participation seem to be more and more important. Core issues in that development included an initial emphasis on labour market participation, followed during the 1970s by the appearance of economic compensation in the limelight, and a decade later, the participation and full social citizenship of disabled people became the focus. Another interesting finding is the change from an emphasis on the family as the basic economic unit, to an emphasis on the individual as the target for benefits and services.

A general conclusion of the thesis is that the construction of C-LDC is a means for regulating and controlling eligibility for support and services. Boundaries drawn to separate the disabled from the able-bodied can be traced back to prevailing societal norms and contextual conditions. As the synchronic analysis showed, specific principles and conditions formed the basis for C-LDC in the different regulations for the year 1995. Hedlund claims that her historical analysis of the disability program shows that C-LDC are being influenced by their social context. As a reader, it is hard to see which parts of the social context she is referring to. It is also unclear how this social context is defined and narrowed down, in order to grasp how and by what mechanisms, it influences the shaping of legal disability categories. This is an important issue because she argues that there is a dynamic interplay between C-LDC and C-NDC. If that is true, one could argue that implementation has to be included in the analysis; the way professionals in the various welfare agencies implement C-LDC may certainly affect the notions that the layman may develop on disability. Implementation forms the link between context and legal criteria.

Hedlund chooses the field of social security regulations in order to explore criteria and definitions used to construct disability categories. This may be reasonable, though she does not explicitly argue for her choice. However, it would have also been fruitful to contemplate alternative programs in order to justify her choice. A (short but instructive) discussion of definitions of disability in other social welfare laws for instance, the social assistance act, ordinances on special measures for persons with work-related disabilities, the employment protection act, the work environment act, etc. might have convinced us that her choice was the best one to make.

Hedlund uses many interesting theoretical perspectives. However, each of them deserves more space and in-depth application than is provided in the thesis (some of them might have been saved for her next book). This piecemeal treatment gives a rhapsodic impression since some of the theoretical perspectives and concepts are not actively utilised for the purpose of clarifying the complexity involved in constructing disability categories. However, her sample of perspectives opens up some interesting options. One idea would have been to relate some theories to C-LDC and others to C-NDC or to the dynamic interplay between the two. The palette of theoretical perspectives including Simmel, Durkheim & Mauss, Foucault, etc., as well as modern welfare state theorists, would have made this an interesting challenge.

All in all, Marianne Hedlund has thoroughly explored the legal requirements for a disability category in Swedish social policy. This is done both diachronically and synchronically – a design that seems to be fruitful and illuminating especially to the extent that legal criteria can be linked to societal norms, moral principles and symbolic understandings. Marianne Hedlund has paved the way for interesting future studies on the complex pattern of definitions of disability in advanced welfare states.

Rafael Lindqvist
Department of Social Welfare
Umeå University
Sweden

Delaktighetens språk *(Language of participation).*

Author: Gustavsson Anders (ed.).
Lund: Studentlitteratur 2004.

The view of what is a desirable life for persons with a disability has changed over a 60 year period. At one time, nationally and globally, it was thought acceptable that persons were to spend their lives in an institution under poor and degrading circumstances. This institutional life became however, at least in the industrialized western countries, the ground for reform. Over these years, these conditions have gradually changed.

The Swedish disability reform started in the 1940s, when ideas were expressed regarding the character of a coming public welfare society. During these discussions the disability movement of the time asked how its need for welfare was to be met. A national enquiry was formed to find an answer to this request. For the first time society had a choice between alternatives regarding how to channel its services, through institutions or modern welfare services. The enquiry suggested that welfare services were to be given the responsibility not only for the public generally, but also for persons with a disability, at least for those with a limited need for support.

The enquiry recognized persons with a disability as citizens, with the democratic right to participation and to use public welfare services. They also hoped that this would lead to a more normal life, like that of other members of society. This new socio-political idea was termed the normalisation principle. But they also had economic arguments for their suggestion. Bringing resources for welfare for the public generally together with those for persons with a disability was seen as the only way to achieve a general welfare society.

With this suggestion in 1946 the first step had been taken on the way to community participation of persons with a disability. During the years to follow, this has gradually become accepted and realised. A momentous decision was taken in 1997 when the residential institution was no longer recognized as a service.

The global disability reform has evolved over the same period. The UN declaration of human rights of 1948 gives the value basis for the position of this organisation, seeing persons with a disability with the same human values and rights as others. The work towards a global consensual perspective on disability took place during the 1970s and culminated with the international year of disability in 1981, its theme being ”full participation and equality”.

Another UN organisation which has recognized the right of participation for persons with disability is WHO. In its recent classification, ICF, this particular concept is given a key role.

When the development has led to a broad acceptance of the concept of participation in the field of disability, it also becomes a perspective from which to formulate questions for research. An illustration of this is found in the book “Delaktighetens språk” (“The language of participation”), edited by Anders Gustavsson. Fourteen researchers from the disability field have contributed to twelve chapters, the common theme being participation.

In one group of chapters, participation in education for children with an intellectual disability in Sweden is discussed. As this concept for many years has influenced the curriculum and schooling for this group, these chapters represent a broad perspective on these matters, in the sense that the topic is not necessarily seen as a disability issue. As pupils in school today represent a wide variation of interests and competencies, a major task for the management of schools is to let participation be a general theme, so that all feel included in the work of the school. Education and participation of children with a disability then becomes part of the work of the school.

Are there then any particular techniques to be recommended to achieve participation for children with a disability? In relation to the previous comment the answer given in this part of the book is that a multidimensional process leads to participation of children with a disability, no factor being more important than the other. A naive view of this social process may have detrimental consequences if one does not pay attention to those factors which lead to exclusion of children with disability. To counter this situation, knowledge regarding which factors in the process will enhance participation of children is a necessity.

Another group of chapters deal with "International classification of functioning, disability and health", ICF, the present classification promoted by WHO. The ambition is to develop a model which enables global communication concerning health issues. This model puts participation of a person in focus, providing a structure with factors which are related to participation of a person. The ambition is to provide an alternative to the previous classification, ICIDH, which differentiated between impairment, disability and handicap. ICF is a model in which the concept of handicap is not used.

Some space is given to a presentation of the classification. However, when reading the chapters one finds several critical views on the classification brought forward. One author points to the risk of ICF being too static, missing the fact that participation basically is a result of an interplay, something which is difficult to describe with this model. Another author finds difficulty in reconciling the social model of disability, deeply rooted in the Swedish approach to disability, with ICF. The model is seen as being too much of a classification to describe health, thereby missing important aspects of participation of persons with a disability.

In the Swedish disability movement, handicap is seen as a relative concept, the result of the interplay between the person with a disability and the demands made on him/her to manage his/her everyday life. Contextual factors hindering a life seen as desirable by the person, are thereby identified and subject to social change. Some of the authors see problems with the fact that ICF does not recognise handicap as a concept, thereby creating risks of weakening the disability movement.

This illustrates that the book essentially contains two parts. One part is a discussion of issues which frequently arise within Swedish services and schools. Participation is a policy which is closely related to disability matters. These are therefore aspects of persons' life which one easily recognises. In this way the analysis of participation becomes easy to comprehend and to incorporate.

The other part of the book presents ICF, the WHO classification. As the ICF classification is relatively new, a large part of these chapters are aimed at a presentation and are therefore rather theoretical. As the ICF aims at being a global model it has a heavy international impact. As a consequence of its international character and its theoretical presentation it takes some time to grasp this aspect of participation if one is not previously acquainted with the classification.

The life of persons with a disability is of course at the core of this concept. It concerns the content of their everyday life and position in society. Participation is therefore a socio-political idea with extensive consequences for actions in relation to persons. The intention with this book is not however to contribute to political actions aiming at a change of life for persons. Instead it is of more interest for the researcher who plans to do a study and who wants to start with a model where participation has a part. In such a situation there is stimulating material to be collected here.

Participation is an expression of an accepted direction of disability activities in Sweden. The development has passed the point in time when separating persons from ordinary life, formally or informally, was seen as desirable. In this situation, disability researchers are faced with a host of new problems which need elucidation. The varied approaches presented in this book are good contributions to a discussion which will continue.

Kent O Ericsson, Ph D
Department of Education
Uppsala University
Sweden