

BOOK REVIEW

Hjælpeordningen – en brugerundersøgelse (The Help Regulation – a User Investigation)

BJARNE BJELKE JENSEN (ED.) & NIKAOLAI EVANS

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During the past few decades, considerable changes have taken place in the Nordic welfare systems and also in several other European welfare states. Despite distinct variations in detail, one can determine a number of common traits in several of the reforms. One is that the changes, to a large extent, have been politically motivated by aims to provide increased flexibility in service production and distribution, and to promote self-governance and free choice for the citizens concerned. Another common trait is that the organizational means used to attain these goals have been decentralization, de-regulation and direct payments. The last mentioned refers to the fact that the reforms have included the provision of economic resources (or vouchers, cheques, etc.) directly to the “user”, who, in principle, has been free to choose from a spectrum of different services.

In some countries, these kinds of market-inspired reforms have been carried out most significantly in the area of organizing personal assistance for individuals with impairments. This is interesting, not just for researchers concerned with impairment and disability *per se*, but also for those with a more general interest in the field of welfare state regimes and citizenship.

The notion that this kind of market-inspired arrangement presents us with a range of outcomes, which it is important to describe and analyse, finds support in this study of social services for people with impairments in Denmark, conducted by Bjarne Bjelke Jensen and Nikolai Evans. In their book, *Hjælpeordningen – en brugerundersøgelse (The Help Regulation – a user investigation)*, the employment and effects of a new regulation, i.e. paragraph 77 in Danish social law, is examined. Since its establishment, this paragraph provides a number of Danish citizens with an alternative to the traditionally organized social services. When starting locally as a temporary administrative regulation at the end of 1970, the local welfare bureaucracies began to disburse economic resources directly to people with impairments instead of, for example, offering them a traditional home-help service or finding them a

place in a nursing home. Today, the regulation is legally established, but it has been the subject of several controversies over the years, such as which citizens should be entitled to this kind of help, for what kind of activities the resource should be allowed, how to find the right formula to estimate the number of hours to be offered per person, and whether this kind of service should be allowed to combine with other types of assistance services (p. 19). Obviously, these are not marginal questions; on the contrary, we may define them as rather basic conditions and limits for participation, empowerment, activity and involvement in the everyday life of people with disabilities.

If we examine the Danish situation in more detail, we may conclude that paragraph 77 of the social law offers the opportunity for people with mobility impairment to receive economic assistance in order to employ their own helpers. This authority includes the tasks of planning the helper's work, supervising them, and managing the administration, i.e. accounting, payment of wages, etc. As pointed out by the authors, the establishment of this kind of administrative regulation and practice has given rise to a wide range of questions about the effects on the citizens concerned. How do people with mobility impairment experience the opportunity to receive social service and support through a system of direct payment? How do they describe their role as employers? Do they describe it as resulting in increased self-governance and a more flexible life? In what way, and in what way not?

Jensen and Evans have addressed these questions by conducting, analysing and presenting results from 28 relatively open interviews with persons from all over Denmark. The informants are all adults, they all have mobility impairment and they have all experienced what it means to be a "user" of the regulation, i.e. paragraph 77 of Danish social law. The authors aim is to investigate what the regulation means to the users "from the perspective of subjective life quality and everyday life challenges" (p. 11). More concretely, they highlight the following questions: What is the regulation used for? What does it give to the users? What does it take from the users? What does it demand from the users? "Our aim is to uncover qualitatively and to document the meaning of the regulation for the life of the user, and to map out experiences from holding the employer's role" (p. 11). The rich empirical material is presented thematically, with a chapter devoted to each theme.

This book is both interesting and important for several reasons. Starting with a detailed and informative description of the background of the welfare reform in question, Jensen and Evans' study presents us with a rich and illustrative treatment of the informants' situations as well as of the possibilities and problems they experience from the kind of service they are offered. Throughout the book the authors' present us with a large number of verbatim quotations. I will try to present the themes briefly below, before continuing with a discussion of the type of presentation chosen and the analysis conducted.

The first empirical chapter mainly considers the informants' expectations and experiences previous to and at the beginning of living with the new service arrangements. Thus, we gain insight into their early expectations of the new kind of help offered to them and into their experiences of setting up

the whole arrangement, i.e. among other things searching for and employing helpers. The chapter also discusses how this kind of service arrangement may affect the type and kind of activities engaged in, as well as the consequences for private life and family life. The predominant impression from this chapter is well illustrated by its heading, "Towards a participatory life", indicating that for most informants the new kind of help arrangement resulted in a more active and comprehensive everyday life.

The following chapter focuses on one particular and, very central aspect of the new kind of service arrangements, i.e. the relationship between the user and the helpers engaged. Here we are presented with concrete illustrations on the centrality of the mood of communication between the two partners. Not least interesting is the discussion of the elusive phenomenon, "personal chemistry". In connection with this we are also given convincing descriptions of the opportunities and risks connected with the development of friendship between the "user" and the helper. In short, this chapter points to the importance and difficulties of finding a balance between closeness and distance, and touches on the many possible traps for both partners in the relationship.

The next chapter addresses another central aspect, i.e. contact between the informants and the street-level bureaucrats in the municipalities. For many informants those contacts seem to be problem-ridden and inflicted by tensions. Even if some persons describe the contacts as primarily helpful and safe, the dominant impression of the testimonies from meetings of this kind is that feelings of insecurity, powerlessness and stress are common among the informants.

The last theme addressed by Jensen and Evans considers a further central component in this service arrangement, namely the employer role. Central in this context are questions about what it takes from the informants to handle the planning and administration, as well as what it takes to find, keep, train and supervise one's helper. The picture that appears is that, for some persons, the tasks mentioned are handled rather conveniently, whereas for others they are rather troublesome to manage.

I hope that I have described the merits of Jensen and Evans' study clearly. As indicated earlier, a primary strength of the text is that it paints a rich and vigorous picture of living with a mobility impairment and the ways in which the new kind of service arrangements may impinge on people's living situation. Since any way of reporting and analysing these kinds of empirical findings has its pros and cons, in the following paragraphs I describe the shortcomings of the book. I will do this by focusing on two different, but interrelated, aspects of the work.

My first comment concerns the way in which the informants' statements appear in the text, i.e. are presented in different chapters claiming to illustrate the themes in question. Although relevant themes have been chosen, it appears that the authors have had trouble using them for structuring the material in a coherent and systematic way. The main reason for this belief is that, throughout the book, we run into the fact that identical or very similar quotations and discussions emerge under several headings in the text. At

times the authors comment explicitly on this detail by saying that one and the same part of an interview may be coded as belonging to more than one category (p. 32) and that “it is hard to avoid over-lapping” given that one and the same detail may be important in more than one theme (p. 14). Far from claiming that this kind of empirical analysis is easy, I do, however, find that the amount of repetition and overlapping at times makes the disposition unclear and the text difficult to follow. It also presents the reader with the question of whether the themes presented really are the most reasonable and what other themes could have been chosen. In the last part of the review I suggest that the overlapping indicates there is at least one important dimension of the material that remains undiscovered because of the thematic structure accounted for above.

One aspect that appears in the informants’ testimonies throughout the book is their experience of insecurity and lack of knowledge of how they should manage problems encountered in handling the service they are entitled to. This is, so to speak, a theme cutting across those, that the text is formally structured around. Even if not articulated equally strongly and in detail by all informants, these kinds of testimonies are relatively well represented. They emerge when the informants are talking about their meetings with civil servants as well as when they are talking about striving to manage the many tasks included in the employer role. Listening thoroughly to the informants, it is clear that several of them are hesitant, even afraid, to tell anyone about their troubles. Furthermore, for some the hesitation appears to be grounded in a fear of being deprived of the service altogether. How can this be?

My belief is that here we are touching upon something very important, i.e. upon the basic foundations on which service arrangements like this one rest. At the start of the book, Jensen and Evans state that the reform has meant that, in principle, as a citizen you are no longer a client of the social system, but an independent organizer of help and support for your own needs (p. 10). I agree that this highlights something fundamental in this kind of welfare reform. At the same time, however, it conceals something at least as fundamental, i.e. that the citizen, in order to be entitled to the service in question, has to submit to a rather detailed examination by the “street-level bureaucrats”. And precisely this fact brings to light the complexities, not to mention the ambivalences, in this kind of service arrangement.

With this focus we may regard it as an indispensable detail to attend to, that the service arrangement studied by Jensen and Evans not only aims to make it possible for the citizens in question to *become* independent organizers. According to the authors, as well as their informants, the arrangements following from paragraph 77 in Danish social law also include expectations, even demands, that in order to be granted the services you have to show that, to some extent, you already *are* a competent and organized citizen.

Precisely this paradox makes the informants’ attempts to communicate some of their problems with the street-level bureaucrats quite sensible. Tasks included in the employer’s role (administration, accounting, educating personnel, etc.), as well as reporting to the bureaucrats the kind of activities

they attend to during a day (or a week or a month), seem to be typical examples of the kinds of situation that are difficult for some of the informants. Why is this so? I suggest that a relevant answer, which is supported by the interviews, is that they feel that if they report too many problems with being an employer or report problems with attending a certain number of activities per day (or week or month), then they risk losing the help altogether – being labelled as not sufficiently competent and active.

A careful treatment of these kinds of questions would, by necessity, have called for a perspective more open for problematizing. As it turns out, the authors claim the results show that the reform is experienced as a success and that it has given persons with mobility impairments a rich and an active life. They also hold that it may be possible to solve the majority of problems that exist by providing information and education. My concluding comments point out some important problems that are probably not so easy to solve by way of education and development.

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