

Introduction to special issue: Quality of services for disabled people

By Steen Bengtsson

This special issue of SJDR has its origins in a conference on the topic of quality of services for disabled people, autumn 2002, during the Danish European Council chairmanship. The reason for choosing this conference theme was that as disability policy develops in the European Union countries, flexible and individually tailored services become increasingly important means for creating equal opportunities for people with disabilities. The quality of services becomes crucial, while also recognizing that much of life quality and well-being is not about services per se. These are complicated issues, including such as the role of policy and legislation at different levels, the role of special and generic services and their organisational contexts, and methodological issues connected to measuring 'quality'. The articles in this special issue build on some of the major contributions to that conference.

Concerning people with intellectual disabilities, the question of assessing quality of services is not a simple one. One cannot assume that quality is something that everyone is able to judge, and nor can one assume that everyone is able to express their opinion. Service evaluation previously was decided by professionals, and since they also were the providers of the same services, this left very little place for different perspectives and a critical look. But the relations between clients and professionals have changed, as *Bea Maes* argues in her article, and service recipients are now more involved in service planning and evaluation. *Bea Maes* reviews different research strategies of quality evaluation, and discusses this from the perspective of people with intellectual disabilities. Her own research has primarily concerned the association of quality of life outcomes with type of service provision and support characteristics. She stresses the necessity of client involvement, and discusses how client involvement can be implemented in the context of services. Furthermore she shows how quality evaluations by clients can direct the way in which services could change. Her contribution focuses on the micro-level. It is relevant in relation to micro-level policy where concrete changes can occur for individuals and their situations, but also has relevance for other levels of policy where societal conditions are shaped and regulated.

Providing quality services for people with intellectual disabilities is not just a question of finding out how to measure quality of life outcomes and establishing a connection between these and types of services. Developing services is also a question of developing the policies and structures of service provision, and this picture is very different among the countries of Europe. Some countries are more open for change and have political climates and institutional structures that make it easier to change, while others may be said to be more conservative and have structures that make change difficult. Germany probably belongs to the latter

group, and in his article *Johannes Schädler* describes some of the difficulties of implementing reforms in the field of intellectual disability in Germany. In a fragmented system such as the German one, quality management easily becomes a 'ceremony for the external world', as he phrases it. Schädler focuses the structural-organisational aspects of services in a historical perspective. He argues that legislation is not enough to accomplish changes, and states that changes in organisational philosophy are necessary. Such changes may have many sources, and one important example is the role of consumer movements such as self-advocacy. Attempts to ensure quality through the legislated quality assurance procedures have not notably changed provision structures in the intellectual disability field in Germany, and he argues that such changes might have been more successful if services had taken more account of the results of quality evaluations based in clients' experiences and perspectives.

Maes' and Schädler's articles are both about intellectual disabilities, where many would argue that the problems of quality are complicated because we cannot simply assume that the users are able to evaluate services. If we consider services to people with physical disabilities or for parents with disabled children, we might expect not to have this problem. We might expect user involvement and user influence to be a much simpler issue. And yet, in reality, that need not be the case at all. Organisational roles and definitions may form and transform reactions so as to produce results that may appear paradoxical. It may be easier for professionals to use sophisticated methods that give a role to them and to professionalism, than simply leaving such roles and instead listening to the client as one human being usually listens to another. There is in any case a need to inject new life into routines for users' influence on services.

We often hear today that standard solutions are not good enough, and that services must be tailor-made. Often the consequence is that the person with disabilities cannot make a single application and get a simple decision once and for all, but is instead forced to go to the caseworker again and again, for this and for that. But the caseworker is not a magician who just can solve all problems and requests. As social service must be delivered by an organisation, the client easily becomes included as the nethermost member in the service system hierarchy, instead of having the central place of the user who should be served. At least as long as the service organisation is not transparent, this is the effect that can be expected. But it is not at all impossible to invent methods that shed light on the situation between caseworker and client. In *Steen Bengtsson's* article, two such methods have been tried: responses from service users were analysed to find the effect of the caseworker involved in the encounters, and 'listening meetings' where parents can express their opinion to the leaders of the social service administration. Also considered are how service organisations can better work cooperatively toward the goals everyone espouses, namely equality and societal participation.

This problem of contradiction between the principle of giving the individual person the type and amount of compensation needed, and the principle of non-discrimination and rights to benefits for disabled people is addressed by *Jerome Bickenbach and Jeremy Cooper* in their article. They approach the problem from

another angle, considering the case of Michael Barry who was so unlucky as to lose his home aid because of budget cuts. This case has been all the way through the judicial system of Britain ending in the House of Lords, and has therefore shed light on the 'needs principle' as it works in practice. They argue that non-discrimination legislation cannot be used for all situations, such as where people with disabilities are in danger of losing services because of budgetary cuts, because it is not possible to compare them with non-disabled persons in a similar situation. Such a 'similar situation' simply does not exist, and anti-discrimination legislation therefore gives no protection against cuts that are motivated by economy.

Is the ideal then a disability policy that gives disabled people equal opportunities as a legally established right and makes the state responsible to pay all expenses in that connection? And is this financially realistic? Costs have generally been growing during the last decades, and as one consequence, redistribution policies have been put under pressure, as *Bjørn Hvinden and Rune Halvorsen* argue in their article. Today there is not much more room for new tax-financed provisions that redistribute resources among citizens. Instead, policies of regulation have become the new trend. Today national disability policies are often in interplay with international disability policy, such as within the European Union. It may be that the future success of European disability policy will depend on whether one manages to develop a mutually supporting interaction between policies of redistribution and policies of regulation.

This special issue includes concrete evaluative studies of services and their direct effects on people, discussions of providers and systems providing services, and also underlying principles and policies. In addition to representing different levels of discussion, the contributing authors also represent different discipline perspectives. Whereas Hvinden & Halvorsen are on the political level of national and European policy, Bickenbach & Cooper represent a more abstract citizenship rights perspective. Bengtsson and Schädler represent different organisational perspectives in services, Bengtsson experimenting with power relationships between professionals and clients and with the dialogue between these groups, and Schädler taking interest in the potentialities of developing and educating professionals. Maes finally supplements the above with adding a pedagogical point of view, with a focus on user involvement in evaluating service quality.

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