

THE SAME RESPONSIBILITIES - BUT NOT THE SAME RIGHTS

Citizenship as perceived and defined by disabled people; A Comparative study between the United Kingdom and Sweden

STAFFAN SANDÉN

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Address for correspondance with author: staffan.sanden@hotmail.com

ABSTRACT

The concept of citizenship was created in Greece about 600 BC, and has for most of the time been treated as a philosophical concept, or as a concept of political science. In spite of the fact that sociologists have taken an interest in the concept in the second half of the 20th century there is hardly any empirical research to substantiate how the common man perceives and defines the concept.

Disabled people to a great extent perceive themselves as belonging to a forgotten sector of society in that they experience administrative barriers, shortcomings in the way individuals and institutions behave towards them, institutional discrimination, being socially dead, etc.

The aim of this study has been to explore how citizenship is perceived and defined by disabled people in Great Britain and Sweden, focussing on the perception of rights and obligations, and how these rights and obligations have been made available to them by society.

The study was carried out as a qualitative study. Semi-structured interviews were conducted with disabled people defined as activists in a disability context (in Great Britain 19 informants, in Sweden 21 informants). The study was carried out in cooperation with the Wigforss Institute, Halmstad University, Sweden, and the Center for Disability Research, University of Leeds, Great Britain.

The main conclusion of the study is that disabled people are knowledgeable on the concept of citizenship, on rights and responsibilities. They also have a strong sense of wanting to fulfill the responsibilities that are inherent in being a member of society, but that, through the lack of inclusion, institutional discrimination, and the rights that they have been denied, they face difficulties in fulfilling these responsibilities.

The concept of citizenship as defined by the common man

Clarke concludes that human beings describe themselves, and understand themselves, in numerous ways, as men, women, selves, subjects, members of ethnic groups, or religious groups, and sometimes as citizens (1994).

Conover et al, in their exploratory analysis 'Conceptions of Citizenship Among British and American Publics', made the statement with regard to the lack of empirical findings, that: "In fact recent political and philosophical debates have an air of unreality about them, because they are being conducted in what is virtually an empirical void" (1990, p 2). Twelve years later Jones and Gaventa came to the same conclusion: "Very little is known about the realities of how different people understand themselves as citizens, and the way in which this impacts on the different dimensions of their lives. Equally, little is known about how rights languages are actually used in situated struggles, by different individuals and groups, and to what effect", (p 28, 2002).

Searching for empirical studies on how people perceive the concept of citizenship, only two more studies have come forward. One of them is Lister et al 'Young people talk about citizenship; Empirical perspectives on theoretical and political debates' (2003). The other example is Peter Dwyers study 'Welfare Rights and Responsibilities; Contesting Social Citizenship' (2000).

For disabled people living with the consequences of their impairments, living in a society that does not understand the implications of disability, 'being a citizen' might have quite other meanings than it has for persons who do not have to rely on, or are dependent on others to cope with the most fundamental and basic needs of daily tasks. To understand this, one has to have a background of what there is inherent in the concept of citizenship, but also how people apprehends, perceives or experience the contents or substance of citizenship.

In 1966 in Great Britain, the disability activist Paul Hunt wrote in 'Stigma, The Experience of Disability': "We are challenging society to take account of us, to listen to what we have to say, to acknowledge us as an integral part of society itself. We do not want ourselves, or anyone else, treated as second-class citizens and put away out of sight and mind" (p 16).

In 1968 in Sweden, disability activist Vilhelm Ekensteen wrote: "Something drastic has as soon as possible to be accomplished to enhance the situation for all disabled people. They have to be incorporated into the community" (p 25, my translation). Ekensteen did not use the language of citizenship, but the meaning of what he wrote corresponds with that of Paul Hunt.

Barton states: "In the struggle for empowerment, disabled people, particularly through the efforts of their own organisations, are endeavouring to move concerns over questions of need to those of *rights*. Nowhere is this more evident than in relation to the issue of citizenship" (Barton 1993, p 239, the authors own emphasis). Oliver further claims that disability means a denial of citizenship (Oliver 1992).

In Sweden, the deliberate use of the concept of citizenship while talking about, or debating disability politics, seems to start in the end of the 1990s. The Swedish Disability Federation (HSO), which corresponds to the United Kingdom's Disabled People's Council (UKDPC, formerly BCODP), when ratifying their programme A Society for all, uses the caption "The Right to full citizenship" (1999). The same year the new government coming into power wrote in a proposal that: "disability politics is changing and has in the future to be pursued from a perspective of citizenship" (1999, my translation) .

The differences in legislation between Great Britain and Sweden are considerable. Sweden has a written constitution. The 1974 Constitution Act regulates the fundamental rights and freedoms of individuals. Great Britain has no written constitution, nor is there a written Bill of Rights. The individual in Great Britain is formally a subject - subject to the queen.

Active citizenship has been around for a long time in Sweden. The Swedish popular movement (NGOs) engaged people in issues concerning political, civil and social rights early in the last century. The importance of the Swedish adult education organisation for this development of citizenship in Sweden is underlined (Pettersson, Westholm & Blomberg 1989). Despite this, has citizenship not been a subject pursued by the governments in Sweden as it has been in Great Britain by the conservative and New Labour governments. Apart from the 'active citizenship' initiatives, and the 'citizens charter' initiatives, taken by the government of John Major, several commissions appointed by successive governments and the Speakers of the Houses of Parliament, have concentrated on the citizenship concept, with regard to the citizens commitment and participation in different institutions of society.

The study

Observing this divergence in how the concept of citizenship was used in the disability discourse in Great Britain and in Sweden, and in the society at large, made me set up a study to see how disabled people themselves in these two countries look upon, or apprehend, the concept. The study was carried out as a qualitative study using a semi-structured interviews guide. While setting up the guide, the starting point were the definitions or classification of citizenship made by T.H. Marshall into the three different areas: the civil, the political and the social (Marshall 1996).

Interviews were made in Great Britain and Sweden with disabled people defined as activists in a disability context, i.e. people who had taken an active part in associations or organisations of disabled people, or in other ways had become more public, taking part in the disability debate. The interviewees were strategically selected. Questions were asked regarding the respondents perception and definition of the concept, if the concept was current in the disability discourse or in the society at large, of their rights and obligations as citizens and what implications this might have for their relations with the surrounding society. 19 interviews were made in Great Britain and 22 interviews in Sweden.

Citizenship in general terms

In scientific literature the question of citizenship is portrayed as complicated due to among many things the lack of theories regarding social rights as social institutions

(Turner 1993). Oliver and Heater concludes "Much of the debate has been conducted in academic language, sometimes in philosophical and sociological terms difficult for the lay person to understand. - - - As a result of all this analysis and argument, many commentators believe that it is just impossible to reach a general agreement on what citizenship should be today. Apart from the complexity of the subject, it has become bound up in mutually incompatible ideological positions" (pp 32-33, 1994). Lister, on the other hand, states that the concept of citizenship has different meanings to different people. How citizenship is defined is intimately dependent in what society we try to attain (1990).

The informants in my study think that it is difficult to give an answer to the question 'What is your personal perception of the concept of citizenship'. One of the informants makes the statement that "the concept is hardly used in the general debate in Sweden. Without any concept of citizenship in Sweden it becomes difficult to talk about it". Another informant states that "Citizenship in the UK is rather a concept and not a reality".

Despite the concept being in dispute, there is a consensus to be seen among the informants in Sweden and in the UK when describing what ought to be included such as access to necessary utilities in society as well as taking part in decision making in society.

Westin calls attention to the fact that the majority at large in Sweden do not make any distinction between national identity, nationality and citizenship (2003). Citizenship has a legal aspect as well as a social form and is also a question of identification with a specific nation or culture. Many of the Swedish informants apprehend citizenship with nationality. One informant says: "My first thought is on belonging to a nation - - to Sweden". But there are others who see it as an identification with a certain grouping av people who identify with a concept.

Frequently recurring among informants from the two countries, and in accordance with the opening quotations of disability literature from the 1960s, are sentiments of not being a full citizen, not being viewed upon by others as full-worthy citizens. Such sentiments have also been recorded by Voet referring to women's views on citizenship (1998), by age and or ethnic background by Rummery (2002) and 'poor people' by Becker (1997).

Several informants in Sweden and Great Britain claim that the concept of citizenship is not current in the general debate and is hardly discussed in connection to disability. They also share the view that the concept is not very frequent in discussions among the general public. They have the belief that discussions are rather carried out in terms of the discrimination that different groups in society face, such as race or ethnic background, gender or disability, than being linked to terms referring to citizenship.

One Swedish informant says: "It depends on what you mean by current. It is not current on the political agenda, and I am not sure it is current on the intellectual agenda. It ought to be of great immediate interest in a discussion on the democratic society and Swedish democracy" (Sw/f-m).

A British informant says: "I think it is only current in a sort of reverse matter. I do not think that most people talk about citizenship. I think people are becoming more and more aware of the discrimination they face. So I think it is a focus on that part of it, where are these discriminations. - - But there is not that I am picking up of a wider discussion of citizenship, of like society saying, where do disabled people fit in, where do black people fit in, where do such and such issues fit in, where do other marginalised and oppressed people fit in?" (B/m).

But there are also claims that the disability movement, in Great Britain, and on a European and international level, is using the concept of citizenship to a greater degree than before. "When talking disability politics we are using the phrase 'citizenship' more and more to emphasise our participation, of rights instead of equal opportunities" (Br/f-m).

There seems to be a greater awareness on the concept of citizenship among British informants compared to their Swedish counterparts. But at the same time there is a general agreement of what ought to be included such as access to necessary utilities in society as well as taking part in decision making in society. Many informants see themselves as second class citizens.

To be a citizen

The question on what it means to be a citizen generates many answers that could be categorized as 'active citizenship', i.e. the respondents wishes take on the responsibility, to take part, to influence in benefit of the society. "I would say that my sense of responsibility in relation to social justice and equality is actually greater than my sense of having personal 'rights' " (Br/f-m).

Sentiments of having a collective responsibility is recurrent, but also the feeling of being a second-class citizen.

Rights

In general terms

From the emergence of the concept of citizenship, rights and responsibilities have been an area for discussions by philosophers. Marshall made the distinction to divide citizenship into three parts, the civil, the political and the social. Each of these is composed of specific rights (Marshall 1996). Rights cover all areas and functions in a society without any consideration relating to time and space.

What does the citizen know about rights? When and how does questions concerning rights emerge, and what significance has the question regarding rights for disabled people?

One informant remarks: "When I became disabled was the first time in my life that I had to ask myself - what are rights in fact" (Sw/f-m).

Another informant says: "I don't think of citizenship in formal legal terms. It is self-evident that one has rights that are equal to what other people have, such as taking part in the political process. When I look upon it from a disability policy point of view I see them as functions in the daily societal solidarity, or fellowship. There are

consequences that arise, when speaking about rights for disabled people, such as different prerequisites. It is about access, not only to the built community, that buildings are accessible and fit for use. That one can sojourn in them as equals. To be able to travel with the same ease as other citizens do. There is acknowledgement in principle that we are citizens as are everybody, but as long as all these prerequisites and requirements are not lived up to, it is just a chimera” (Sw/m).

Many informants illuminate similar problematic areas. Organizational and economical shortage creates boundaries to the access to certain social and civil rights, that other people are in access of, and for whom this often is self-evident to have.

Not only down-to-earth questions are of importance to the informants. Purely existential questions are also brought to light, such as the right to influence, ascendancy in matters of vital and decisive importance, such as the right to life for disabled people, the right for disabled people to parenthood etc.

On the question if one could rank what rights are the most important, the informants response varies from, that the question in it-self is absurd and that one can not, and should or ought not go into a discourse debating if one form of right could be placed before or after another form of right, to answers that give examples of items of importance, but also point at the problems that disabled people face when trying to access these rights.

“I do not believe one can, and I do not think personally that one should get involved in a discourse which suggest one might. Is it more important to have a right to use a bus than it is to have a right to have a job. I mean I think those are absurd debates. Either one is a citizen or one is not” (Br/m).

“I would say they are equally important, access, financial security, having enough to eat, comfortable home, accessible transport, access to social activities and opportunities to interact with others, and I would say that they are equally important for disabled people, except that disabled people do not have access to many of these things and therefore it becomes a question of priority in terms of what makes a reasonable quality of life and what makes everyday living sustainable” (Br/f-m).

On the question if one could draw borders or make a distinction on what social rights an individual would be entitled to, many informants answer that one could set a limit for what a society could afford, but that is not the same as setting up a border for one individual citizen or groups of citizens.

Many of the answers given on questions concerning rights are about prerequisites necessary for individuals to enjoy, or to be able to live their citizenship. Society could draw borders on what it could afford, but can not draw borders for what individual citizens or groups of citizens should have access to.

Political rights

The informants are well aware that from a formal point of view all have access to the political rights inscribed in the laws of the country, such as casting their vote at general elections. In practice for many disabled people with varying impairments,

such as hard of hearing, visually impaired and blind and mobility impaired, there are difficulties in getting current and readable information from the ongoing political debate in radio and TV, getting access to the voting booth, casting their vote in secrecy etc, etc.

Many informants also point out the lack of interest that political parties show in involving them in the political life. Not only lacking access to premises used by the party organisations, there are generally no hearing loops, the agenda and documents for the meeting are seldom supplied in anything else than in black and white print. There is generally a lack of interest in 'waiting' for the person with speech impairment to conclude his contribution to the meeting.

At the same time many informants stress the responsibility that the disabled person, as well as the disability movement has, to make it possible for disabled people to partake in the political life of society, not only in matters pertaining to disabled people, but rather in the development of questions of importance to all members of the society.

Civil rights

Many informants see questions concerning civil rights, individual and personal rights, rather to be questions referring to human rights. Of special concern to them are 'existential' matters, such as the right to parenthood, abortions of impaired fetuses, fetal anomaly diagnostics and euthanasia. Another line of answers refer to how their right of and competence for making decisions concerning their own life often is called in question.

Social rights

Barbalet has written that: " - - the right to social goods and services might simply improve the conditions of the disadvantaged without directly dealing with the underlying causes of inequality" (p 38, 1993). Lister notes that: "The other main justification for recognising social rights as a legitimate expression of citizenship is that they help to promote the effective exercise of civil and political rights by groups who are disadvantaged in terms of power and resources" (p 16, 1997).

The answers given to questions concerning social rights contains rich descriptions of flaws or deficits in every respect of equality as compared to non-disabled people. The informants also show that lots of energy has to go into the struggle to explain and to defend the rights to go to main-stream schools with your peers from the neighbourhood, instead of being sent off to special schools, to access equipment, tools etc that should be provided to you to simplify and facilitate for you as a disabled person to take part in the doings of the society.

The response from my interviewees show that society has not been able to eradicate what is lacking or is at fault, despite being aware of these problems for several decades. The essence of the answers given are that as a disabled person one has to fight every day of one's life to come near the rights supposed to be inherent with citizenship.

Responsibilities

The same way that rights have been discussed over hundreds of years, has the question of the responsibilities of the citizen been an object for the philosophical debate.

In the literature of political science and sociology on citizenship there is quite a lot to be read on the fulfilment of responsibilities as a condition for citizenship. Marshall wrote: "If citizenship is invoked in the defence of rights, the corresponding duties of citizenship cannot be ignored. These do not require a man to sacrifice his individual liberty or to submit without question to every demand made by government. But they do require that his acts should be inspired by a lively sense of responsibility towards the welfare of the community" (p 41, 1996).

During the two, three latest decades the interest for the question of the active citizen has increased. In Great Britain the conservative party as well as the New Left have adopted this concept (Oliver & Heater 1994). Kymlica and Norman state that: "The literature on citizenship is full of dire predictions about the decline of virtue" (1995, p 301)

Is it possible for a disabled person to carry out the duties that come with citizenship?

One Swedish informant remarks: "In the debate we have sometimes been told, when we demand our rights, 'yes you will have your rights, but it is a question about rights and responsibilities'. We have then been annoyed, as our experience is that one wants to place responsibilities upon us, before we have the opportunity to exercise them. Open up the society so that we can take part to the full. We are fully aware that participation means both rights and responsibilities. To exercise one's responsibilities is a right" (Sw/m).

A British informants response to the same question is that: "Who is it to decide what responsibilities and obligations an individual should have? It is easy for people in position of authority and power and wealth to talk about individual responsibilities, and exercising those responsibilities. But coming back to the way society is structured in it's present context, we do not have an equal education system, we do not have equal access to resources, and some people connect societies responsibilities and demonstrate they are responsible citizens far easier than others?" (Br/m).

Are there alternative ways or forms possible to fulfill these obligations? One informant concludes that he takes part in the household, doing his share, through his personal assistant. In that way he is able to take up his rightful and legitimate place not only in the family but this also makes it possible for him to voice his opinion on different matters.

The informants are very clear and distinct in saying that they have responsibilities to the same extent that other citizens do, and that one is responsible not only for oneself but also for other people in society. Several informants also stress that it is a right to exercise one's duties, but that they often lack the prerequisites to do that.

The good citizen

A citizen is not only provided with rights and is expected to exercise his duties. A 'good' citizen in its deepest meaning is one who feels moral commitments to the society, and performs those responsibilities that follows with being a citizen. But what is 'good' and what attitudes should an individual have, and what deeds are to be performed to entitle someone to call himself 'the good citizen'. Are there good citizens and is it easier or more difficult to be the good citizen when being disabled.

One informant says: "It is more difficult to be the good citizen when being disabled, because it means using more violence, more force, on one's own integrity, to give up many more of one's wishes and demands" (Sw/f-m).

Another informant tells: "There are different levels of action and each of us makes our own contribution in our own way. I think a lot of problems happen when we are forced into exercising citizenship in the public sphere when it is not the way that works best for us. - - - One of my worries about the disability movement is that it consists of the public activist, politically organised disabled citizens, in such a way that it effectively silences those who for different reasons do not fit within this model" (Br/f-m).

A common consent among my informants is that it is the responsibility for all citizens to be loyal to the society and not break its laws, but also to let self-interest stand back for the common good. At the same time many have the feeling that disabled people are looked upon as passive recipients of care and charity. This is a fact not only for able-bodied people, but for disabled people as well.

Work as prerequisite for citizenship

The question of work obligation or work ethic has been pursued by many writers and governments as well. Some have made the claim that welfare subsidies make people less inclined to work, whilst others have rejected this view (Becker 1997, Twine 1994, Jordan 1998, Wilson 1994, Dwyer 2000).

A fundamental belief in western societies is that to have a job in interaction with others is of essential importance to the quality of life and the feeling of involvement in the affairs of the community, and that having a job is the foremost important condition for the experience of being a citizen.

On discussing the significance of work for the citizenship of disabled people Abberly (1999) wishes to see a theory of oppression with a notion of social integration that is not dependent upon impaired people's inclusion in productive activity.

The Swedish government notes in 2005 that the labour market for disabled people has deteriorated over the last few years. The British government also states that disabled people has a low rate of employment: "Only one in two disabled people of working age are currently in employment compared to four out of five non-disabled people" (Prime Ministers Strategy Unit 2005, p 42).

The informants are very clear that the concept of work as a prerequisite for citizenship is a too simplified notion.

A Swedish informant responds to the question that: “I do not think that work and citizenship has anything with each other to do. Work is a separate question. It is our Lutheran tradition that tricks us into believing that work is the same as our identity” (Sw/m).

Another informant says: “Work represents very much of the participation in society, but it is very one-sided. There is social life, there is culture and family, home and leisure and all that. I have now and then expressed the reflection that when we can see disabled people working and supporting themselves at about the same level as the population in general does, then one could say that we have reached full participation” (Sw/m).

Update 2006

A few of the informants that I interviewed in 1998-1999 were contacted in 2006, to get an update on their views of being disabled and citizens in Great Britain and in Sweden. Since the initial interviews were made many things with bearing on disabled people have taken place in both countries. At that time there was not any anti-discrimination legislation in force in Sweden comparable to the Disability Discrimination Act (DDA) in Great Britain. Since then anti-discrimination legislation has come into force in Sweden, and the legislation in Britain has been amended too.

The governments in the UK and in Sweden have both come forward with long-term planning with the intention of making adjustments and changes to and at different levels of society eliminating barriers, so to enable disabled people to take part in all aspects of life in society. The Swedish plan, published late in 1999, was named ‘From patient to citizen’, and the corresponding plan in Great Britain, named ‘Improving the life chances of disabled people’ was published in 2005. In the foreword Tony Blair states that “This report (therefore) sets out an ambitious vision for improving the life chances of disabled people so that by 2025 disabled people have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society” (p 6).

The informants contacted were very clear that, despite modifications and amendments to legislation and the governmental long-term planning, very little had changed and improved over the six-seven years that had passed since the interviews were made. They considered themselves to be no more citizens in 2006 than they were in the end of the 1990s.

Summary

There is a distinct difference between Swedish and British interviewees when answering basic questions concerning the concept of citizenship, how current the concept is etc. In Sweden the respondents to a greater degree connect citizenship to nationality, rather than to the relationship between the citizen and the society. British respondents, to a higher degree, use concepts about marginalisation of humans, exclusion etc, i.e. describing their experiences of citizenship in terms related to disability politics.

Many respondents in the UK and Sweden perceive themselves as ‘second-class citizens’, although not all of them see a connection between obstacles they face in

daily life and infringements in their citizenship. Despite this difference, they are unanimous when describing what ought to be included getting access to the utilities of society, as well as taking part in the decision-making in society.

The informants in this study are very clear and eloquent in their answers on the responsibilities that a citizen has, and they point out duties/responsibilities/obligations before rights. But they also point at the necessity of rights being fulfilled so that they will be able to meet their obligations. Several informants mark that they would rather talk about their liability than their responsibility.

Conclusion

While talking about rights, the informants do that in terms of political, civil and social rights, and when talking about responsibilities they do that in terms of being responsible for fellow citizens, with a moral point of departure as active citizens in the society.

‘Active citizenship’, has been and is on the political agenda in Great Britain to an extent that has no equivalent in Swedish politics. This seems to be the answer to the differences observed how the concept of citizenship is perceived by British and Swedish informants.

The other contrariety noted, the difference in language used by the informants in the UK and in Sweden to describe their experiences of citizenship, is probably a consequence of that the social model of disability is dominant in the UK. The social model is much more of a political tool in the disability discourse, than what characterizes the relational model of disability, that is general in Sweden.

The main conclusion of the study, bearing in mind that most of the informants in this study belong to the group of ‘top dogs’ in the disability movement in Great Britain and in Sweden, is that disabled people are knowledgeable on the concept of citizenship, on rights and responsibilities. They have a strong sense of wanting to fulfill the responsibilities that are inherent in being members of society, but that, through the lack of inclusion, institutional discrimination, and the rights that they have been denied, they face difficulties in fulfilling these responsibilities.

It is not a ‘differentiated citizenship’ that disabled people are demanding, it is to be included into society on equal terms as able-bodied people are.

Future research

To reach a greater width and depth of the perceptions on the concept of citizenship, a further study is being planned. This will focus on disabled people who are not members of disability organisations, or not active within the disability movement.

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Abbreviations used in connection with quotations

(Br/f-m) (Sw/f-m) British female, Swedish female
(Br/m) (Sw/m) British male, Swedish male