

'SOON THERE'LL BE A SOCIETY FOR EVERY BIT OF THE INTESTINE': the complexities of positioning disability in Sweden today.

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Abstract: This article addresses the issue of the dual situation in which disabled people find themselves in modern society. On the one hand, people are increasingly grouped according to ever more precise labels. The political system demands this emblematic organisation. The article discusses the growth in the number of new, high-profile organisations and how this relates to the political system in which such organisations are needed as 'dialogue partners'. On the other hand, naturally one finds that in different social contexts there is some opposition to categorisation and labelling.

The strong profiling and articulation of disability are thus factors at the political level. This article addresses in the first instance the new, politically distinct mode of labelling. However, there is also a discussion of the way in which individuals' articulated descriptions of their own disabilities demand a response at levels other than the political.

The article is derived in part from a study dealing with the way in which organisations for the disabled present themselves. The sources for the study were printed material, leaflets, internal memos, and newsletters. These have been supplemented with further material in the form of interviews recorded with active members of the various organisations studied, notes made on association meetings attended by the author, plus a questionnaire responded to by forty organisations. The results of the study have been published in Sellerberg (1993) and there is further analysis in Sellerberg (1996).

The results of this empirical study are here discussed in the context of recent work by Swedish political scientists on the organisations' changing role in the Swedish political system. The demands of labelling are related to the new situation that they have described. This article considers a situation that is full of contradictions, and discusses the consequences of recent developments. In doing so, the possible consequences of recent changes are analysed on different levels: the way in which this contradictory situation is experienced; the ramifications for fairness, in other words how the situation affects disabled

people in different circumstances; and the consequences for individual relationships with the various public bodies involved. Finally, the question is asked whether this is a new social type of presentation, something that disabled people must make use of to maintain their visibility, even their very existence, in today's socio-political situation.

Modern society thus seems to place the disabled in a dual situation. On the one hand, people are ever more grouped under ever more precise headings, or 'labels'. The political system demands high-profile 'dialogue partners'. On the other hand, there is some opposition against categorisation: vague rather than specific terminology is used when naming disabilities.

Articulation and labelling

There is currently a constant stream of new disability organisations. The older, larger organisations are critical of the increase in the numbers of new groups forming around increasingly specific diagnoses or problems. It is this development that has been typified as the 'disabled jungle' (Wallin, 1983:11-12:5). Wallin, writing about the efforts made by disability organisations to differentiate between themselves and to define their own particular goals, notes that: 'If it had been a business that was being discussed here, a thorough restructuring would have been called for long ago. But people who have become engaged in social and medical problems find it difficult to accept that their ideas

should merge with other people's' (Wallin quoted in Sellerberg, 1993:23). One indication of the sheer number of organisations is a list compiled for one of the Swedish County Councils - the government bodies that provide, finance and administrate public health-care in Sweden - that includes 101 different newsletters issued by organisations for and of disabled people (*Patientföreningar, Handikapporganisationer, Stödföreningar i Skåne* 1997).

A growing number of organisations and groups are being formed, each specific to a disability, disorder or diagnosis, each articulating its own problems. Groups have to differentiate between themselves as far as is possible, and this brings with it a more comprehensive exclusion of those who do not face exactly the same problems. One statistical survey shows that such organisations are prone to splintering (Falkenhaus, 1997:7:17). Falkenhaus draws parallels between established political parties and the divisions experienced in 'single issue movements'. It probably only requires a small 'slip' in a precise, diagnostic presentation for it to become associated - erroneously - with 'kindred' disorders or disabilities. Anspach writes that modern organisations of disabled people are engaged in the *politics of identity* (Anspach, 1979).

Analyses of the Swedish situation thus stress that it has changed rapidly over the last few decades. This change has been general, not only affecting disability organisations. In Esaiasson's

view, Sweden has shifted from a corporate system to a pluralist - or 'lobbyist' - system (Esaïasson, 1998:15). Previously, interest groups co-operated with the government. The larger organisations were involved in political decisions by their presence on governmental boards of enquiry, and their significant role as consultative bodies for government legislation. This can be characterised as a corporate system of influence. Esaïasson, who has studied organisations' participation in governmental enquiries, concluded that their presence is now much less self-evident. He emphasises that there has been a change of system, so that today the traditional means of exerting influence have become less and less feasible (Esaïasson, 1998:15). Organisations can no longer act within the political system, and instead it has become much more important to lobby politicians, both formally and informally. Organisations dissolve into splinter groups, and act from outside the political system

Within the disability movement a degree of competition between the various organisations is considered acceptable. Each has to compete in new ways for both society's resources and the public's attention. The organisations cannot only 'focus inwards' if they are to gain support for their members; in today's society they have to 'speak' to the authorities, politicians, the mass media, and the public in general. Different impairments and disorders, each with their carefully articulated diagnoses, require 'spokesmen' at an

organisational level. Froestad (1995) has described the manner in which the current system of social services places rigid demands on sick and disabled 'users'. Their organisations are obliged to interact with the public authorities. Froestad (1997) has shown how these groups can function today as 'mini-versions' of socio-economic classes, stressing that these class presentations are understood - and answered - by central government.

This is the same approach that Stone (1985) has suggested: disability is neither a medical nor a legal condition, but a political one. Precise categorisation becomes a distribution mechanism in the socio-political system, a 'language' that disability organisations are forced to use.

Emblems - socio-political labelling

The material indicates the presence of a new direction in the way in which these groups present themselves, here described as an *emblem*. They assume a brief, pithy name. Members are apt to call themselves 'panics', 'SLE-ists', 'scoliotics', 'stomics', 'arthritics', and so on. Occasionally the name will have an ironic ring; the Swedish word for 'idiot' invests the term for a polio sufferer, 'poliot', with a facetious ring. Those with hearing impairments who have undergone cochlea-implant operations call themselves 'the plants and the children's sub-group is known as 'the baby plants', while an organisation for people diagnosed with HIV has adopted the name 'The PositHIVE

Group'. These are among the names carefully chosen to make an impact that Ronström (1995) terms emblems.

This self-characterisation constitutes a delimitation or *demarkation* in itself, making the group an entity apart. It also implies a clear exclusion of any adjacent, but otherwise irrelevant, diagnosis. For example, the newsletter for those suffering from panic is very careful to emphasise that their readers' disability is 'not due to any somatic disorder, or to a mental disturbance such as clinical depression, somatisation, or schizophrenia. The disturbance is not connected with agoraphobia'. (*Tidskrift för Paniksyndromsällskapet*, 1993:1, my italics.)

The presentations are often strikingly *matter-of-fact*. In a competitive atmosphere, it would be natural to expect disability organisations to present their respective disorders in a dramatic manner, describing harrowing cases. Similarly, it could be assumed an organisation would want to depict its members as being in a worse situation than others, with greater needs. Therefore, the matter-of-factness that actually characterises these presentations is remarkable. Why these meticulous, precise descriptions of what it is like to live with a disability? Perhaps one explanation is to be found in the fact that the organisations know they will continue to compete within the same social system. Many of them are members of an umbrella organisation, the Federation of Disability Associations (*Handikappades samarbetsorganisation*,

or HSO). The future will thus bring collaboration as well as competition. In these circumstances, an organisation that pushes its case too hard, resorts to over-dramatic means, or plays too ostentatiously on people's feelings, stands to lose credibility. Simmel (1964) discusses this tendency to restrict spectacular manoeuvres in a competitive situation. The toughness of the competition frequently leads the competitors themselves to impose limits. The newsletters discuss campaigns that went over the top in presenting the problems associated with the disability or disorder concerned. Representatives of the organisations note with regret that accounts of authentic cases are sometimes necessary to foster a genuine understanding on the part of the authorities and people in the member's environment.

New power - choosing your own label

Organisations are founded, organisations sub-divide. Naturally, the strength and initiatives the numerous new organisations bring to society are important, as is the fact that people with the disabilities and disorders classify themselves in their own organisations. In doing so they formulate and prioritise their own problems. Several researchers have described the important shift in initiative that occurred when disabled people formed their own organisations that formulated their own problems. Höglund has analysed the history of the process in the organisations for/of deaf people and

people with hearing-impairments. At first it was the 'outsiders' - specialists, medical staff in general, or relatives - who ran the associations, not the deaf or hearing-impaired them-selves. Only later was the work of running such organisations taken over by the very people they were intended to assist, those who themselves were disabled (Höglund, 1993). They presented themselves with the help of the organisation: 'This is the way we are. These are our needs'. A new initiative with regard to definition grew within the organisations. This evolution also meant, however, that disabled people defined in this way participate (and *have* to participate) in society's apparatus of power.

Labels at other levels

It has long been assumed that people who are in any sense deviant are eager to escape the terms that label them. An important element in this debate is the question of how we can prevent people from being branded and stigmatised on the basis of unfavourable labelling. A great many researchers, for example, stress the negative consequences of labelling mental illness (Scheff, 1975; Cumming and Cumming, 1957; D'Arcy and Brockman, 1977). But in this article a situation has been outlined in which sick and disabled people endeavour to present profiles of themselves in which the fact of their disability is fundamental.

In this context it is important to separate the analytical levels. On the

one hand, at the organisational level organisations for specific disabilities and diagnoses develop articulations and definitions of their specific problems that are aimed at an audience of outsiders. At this level disabled people formulate representations and choose telling names. They call themselves 'scoliotics', 'arthritics', 'poliots', 'panics', and 'plants'. The symptoms of a disorder come to have an emblematic meaning (Ronström, 1995). The outward boundaries are carefully marked off; others do not belong, and efforts are made to prevent them from gathering under the same 'emblem'. At the political level, the organisation 'addresses' its socio-political surroundings. Questions relating to the organisation's profile are given prominence. Issues and programmes are formulated, sit-ins are arranged, politicians are lobbied.

At another level, however, disabled people protest against the terms used to describe their disability. They argue that the names perpetuate pigeon-holing and stigmatisation. Enerstvedt (1995) rehearses the recommendations in *Words with Dignity* on how to refer to peoples' disabilities, and here it is *not* a question of emblematic function and potent naming within an 'organisational dialogue' that is 'directed outwards'. This tendency has been described by Zola, who stresses the reluctance of disabled people to assume 'labels' based on disability. 'While most minority groups grow up in some special subculture and thus develop certain norms and expectations, the

physically disabled are not similarly prepared. Born for the most part into normal families, we are socialised into that world. The world of sickness is one we enter only later, poorly prepared and with all the prejudices of the normal. The very vocabulary we use to describe ourselves is borrowed from that society. We are de-formed, dis-eased, dis-abled, dis-ordered, abnormal, and, most telling of all, called an in-valid. And almost all share deep within ourselves the hope for a miracle to reverse the process, a new drug or operation which will return us to a life of validity' (Zola, 1982:206).

False prognostications

Society has thus moved towards increasing numbers of organisations with clearly articulated profiles that act as emblems for the group. This organisational development seems to have been unforeseen, however. A decade or so ago several researchers assumed that disability organisations. 'Persons with disabilities often are understandably reluctant to focus on that aspect of their identity that is most negatively stigmatised by the rest of society and to mobilise politically around it', wrote Hahn (1985:310). Other researchers argued that disabled people had low self-esteem, and that this would prevent them from organising themselves (Zola, 1982:207-208; Goffman, 1963: 112-114). This line of reasoning emphasised how difficult it was to gather under a banner that was viewed with distaste by society at large. Zola

(1982), for example, stated at the start of the 1980s that disabled people lived in such circumstances that the conditions necessary for collective action quite simply did not exist. He argued that they were so spread out geographically that they could not readily meet; moreover they were not able to formulate their shared interests. Even Scotch, for example in 'Disability as a Basis for a Social Movement', enumerates the obstacles at several levels that block the formation of organisations by disabled people: they are widely dispersed; they often only mix with people without disabilities; they all face very different problems, and there is rarely a common cause for their disorder; they have problems with education and work because of their disability; and people with disabilities do not share a social background, but come from different classes (Scotch, 1988:161). Scotch adds that many disabled people have a tendency to 'role distance' themselves by simply refusing to see themselves as disabled. They have no wish to identify themselves with the group, even less to act on its behalf (Scotch, 1988:161). There is resistance to grouping together under a name that is based on a disability, argues Zola (1982:206).

The sociologists who speculated about the future of these organisations were to be proved wrong. In the event, there was to be a constant stream of new groups formed around ever more specific diagnoses and disabilities. Boyte (1984:116) can be quoted here:

'Thus the story of how a movement of self assertion among the disabled emerged in the 1970s and continues today involves an exploration into changing self perceptions as well as dominant social attitudes'.

The reason for the false prognostications was that they were made at an analytical level that was not suited to the business of drawing conclusions about events at a political level. Analyses, by the likes of Scotch, Hahn and Zola, were based on the relationship between the environment and the *individual*. Stone (1985), on the other hand, concentrates on the socio-political level. She argues that different countries at different times develop different types of 'disability programmes' that all demand disability categorisations, even a hierarchy of categories. However, she does not go into the way in which disability organisations respond in such socio-political dialogues nor the consequences of these responses.

The development of an organisation must, thus, be analysed at an *organisational* level. My hypothesis is that in many countries today, among them Sweden, an entirely new situation has emerged in which collective formulations of this kind must operate. The authorities and various socio-political, social, and medical services *need* disability organisations as partners. The organisations are today involved in a 'societal conversation'. In this new situation, disabled people demand organisation and a definition of what disability really means in order to be

able to act and 'speak' to the community. The many organisations that already exist spawn many more, and each focuses on increasingly specific diagnoses and problems. At the same time, the larger organisations are losing members (Falkenhaug, 1997:17). When the number of organisations increases, naturally competition increases (Sellerberg, 1996:5-35).

The paradox

In getting across a clear picture of a disability, communicating the special problems faced by members and the way in which they are distinct from those of other groups, all organisations have to use a similar language and similar forms of presentation. This paradox, described by Ronström (1994), characterises the organisations' presentations at a socio-political level. He argues that the organisations have to emphasise both the fact that they differ and the ways in which they are different, all the while using the same media and the same methods. 'To put it in somewhat more general terms we could say that all groups which strive to be recognised as different or special in modern society must do this in the same arenas as all the other groups. Paradoxically, they must fight for their rights to be different using the same kinds of forms, genres and repertoires as the others, or else they will have to face the risk of not being recognised, perhaps even being invisible. By performing in the same arenas, with the same expressive forms, the differences

between the groups are temporarily reduced. They thereby become comparable, or compatible, and more similar' (Ronström, 1994:24). Ronström's study was concerned with special interest organisations in general in Sweden today.

Previously, organised special interest groups in Sweden worked in conjunction with the state. Large organisations sat on governmental boards of enquiry and vetted proposed legislation. Today the organisations have to compete, 'fighting' for political interest (Esaiasson, 1998:15). Their literature deals with lobbying political parties, the government, and the various authorities (Lövgren, 1996:5-6:4). To gain recognition, the organisations have to participate in a socio-political system that will not accept any old partner for a dialogue. Organisations compete for the opportunity to 'get their message across', for a chance to bring their presentations to the attention of socio-political entities and authorities. Thus, despite the importance of differentiation to the organisations, one finds great similarities in the construction of their emblems.

The presentations appear to share certain typical characteristics. One feature that is common to all can be distinguished: all the presentations use precise names and 'emblems'. The organisations label themselves 'scoliotics', 'poliotics', 'phobics', and the like. Such self-labelling is often connected with a list of clearly stated problems. Another characteristic is that the boundaries are

clearly marked that define one group in relation to another whose members have a disorder or symptoms that are similar but not 'relevant'. By having virtually the same remit - and the same means of expression - the differences between the groups are reduced. At the same time, it is important comparisons remain possible. Here we have a case of competition between groups who are all in the same boat.

New lines of research

In Swedish society today, it is thus important to analyse both the unifying and divisive positioning of a disability. Firstly, there is an overarching level that Enerstvedt describes in his discussion of *Words with Dignity* by the President's Committee on Employment of People with Disabilities. Secondly, there are the organisations, with their activities and 'dialogues' at the socio-political level. Thirdly, there is the interpersonal, interactive level that for example was identified by Goffman in *Stigma* (Goffman, 1963).

The relationship between levels

One of the main issues is the inherent contradiction in the situation: disabled people must have a strong voice within each organisation to formulate their own labels and to compete with other organisations in putting across their group's needs; on the other hand, at the interpersonal level one finds disabilities labelled in a way that is still disparaging, and which provokes strong reactions from persons

with disabilities. It behoves us to look more closely at this new form of 'status inconsistency'.

Another pressing question concerns the way in which the different levels interrelate. We have already touched on the question of conformity, the element common to all levels. Further questions must be posed with regard to the interplay between the levels. Recent developments display the organisations' vitality, power, and initiative, but we have yet to ask *how* this new situation at the organisational level affects the social situation of individuals, and perhaps places new demands on them. Only then can these questions address the more concrete level, for example, the effect that a powerful disability organisation can have on its members' circumstances.

The individual versus the system

Research, however, can also be directed towards more subtle, latent effects. What is the effect of such a system - in other words, the existence of a vigorous organisational level - on the individual disabled person's position as an actor in the socio-political system? Is it the case that the system has been so constructed that largely it does not 'speak' to individuals, but rather to organisations? Or is it in fact the case that, faced with this new situation, individuals have to be able to formulate themselves as an organisation, to 'speak' as an organisation? Is there today a greater need for individuals to be active, aware, and

competent in presenting their own problems? In her dissertation *Ett liv att leva* (A life to live) Jarkman presents interviews with parents of children who have the condition known as yelomening-occle. From the parents' point of view, dealings with the authorities were far from simple. She describes how they learnt to make the condition socio-politically presentable. And they *had* to learn. Jarkman quotes their observations on how to succeed in these presentations: 'Those who are pushy and can look after themselves, they can probably make the most of it, but those who aren't probably have a tough time of it' (Jarkman, 1996:165). Jarkman's interviews show that different situations require that the disability be presented in different ways. Furthermore, the parents have to be 'on their toes'. Situations change. Current government policy and the personal opinions of individual social workers together create new circumstances that the parents have to deal with; whatever was the case before, may not be the case now (Jarkman, 1996:166). The organisations' newsletters, leaflets, and meetings frequently give advice to individuals on how to deal with the authorities. Can it be that new skills and habits are also required in the interaction between the *individual* and the socio-political system in this new societal context?

Lewin describes the problem of recent legislation that places the onus of demanding assistance from the social services on the individual.

Individuals who have an organisation behind them are in stronger position and stand a much better chance (Lewin, 1998:225). Do the social services - indeed the whole socio-political system - now require that a disability is presented in a distinct, problem-oriented manner?

Organisations publish leaflets, newsletters, 'dictionaries', and glossaries, all offering their members an opportunity to present an articulated self-image or label. You can get help finding out which your label is, and are then warmly encouraged to use it. One hypothesis - derived from the work of Jarkman and Lewin - is that individuals are now required to be able to make much more use of their organisationally articulated labels. Equally, there is a discussion of how disabled people should protest against being seen in terms of a label that is derived from their disability.

Justice and access

A third line of research concerns justice and access to socio-political interaction. Firstly, there is the question of equity and the differences between the organisations in receiving just treatment. Some disabilities are simply more poignant and are thus easier to present than others. Some also have extra help in the form of so-called 'faces'. When celebrities succumb, organisations report that suddenly journalists are on the phone asking what it is *like* to have that disorder or that disability. The disability becomes better known.

In a situation where outwardly directed articulation is important, we have to pay particular attention to those with disabilities that do *not* feature in the socio-political dialogue, those that find it hard to make their voice heard.

In the presentation of disability, specific problems and needs are formulated. Here one will often find a more or less open call for justice. Each organisation sets out its particular right to participate in the socio-political interaction. Consequently, its printed material - newsletters, advertisements, leaflets - describes the disability or the disorder in ways that are intended to bolster the organisation's legitimacy as an actor-competitor in the public arena. Sometimes the sheer number of sufferers is stressed, especially if the disability or illness is a common one. Another way of legitimising their presentation is to point out that far more people are affected than is commonly realised; the illness or disability is hidden. Figures in self-presentations vary: 'there are approximately 14,000 people in Sweden who have had stoma surgery'; the country has '250,000 infertile couples', that is, '15 to 20 per cent of all couples of a fertile age'; 'allergies' affect 2 million Swedes (the total population being just over 8 million); and 'more than 1 million Swedes suffer from rheumatism'. Presentations also emphasise that anyone may be afflicted, including - where applicable - children and young people. Advertisements appear in the daily papers, often in the form of short, repeat notices, consisting sometimes of

only a few words such as '1,500 children suffer from rheumatism'. Campaigns and periodicals serve to stress the unity and concentrated purpose that characterises an individual group of disorders, giving us, for example, the 'Year of the Diabetic', allergy campaigns on television, and the like. Presentations may also stress the random nature of the disorder or disability concerned. In one example we find the quote: 'Imagine a school with five hundred pupils. Statistics tell us that five of them will develop schizophrenia. Which ones? Hard to tell. This illness doesn't care about gender, nationality, or social background' (Advertisement by the Schizophrenia Association in the 'Puls' section of the tabloid newspaper *Aftonbladet*, 1997:09:19:30). Unsurprisingly, in such a system it is difficult for rare, unknown conditions with only a few, perhaps elderly, sufferers to become forceful 'dialogue partners'.

Formulating disabilities to 'exist'

A disability must therefore be articulated 'correctly'. However, the people involved in this articulation have a disability or a disorder. Some, of course, have no problem being 'out there', but others find it very difficult to champion their own cause. What will happen to the groups of disabled people who do not have any particularly significant chance of courting public opinion or seizing the political initiative?

Within this system an increasing number of interests have to formulate

individual arguments. They have to be 'dialogue partners' for the government, local authorities, big companies, and so on. Individual disabilities *have* to participate in this dialogue at the organisational level. The socio-political system offers, for example, the possibility - albeit a limited one - of having a centre of excellence, financial support, and so on. It is a system that demands both activity and wariness. When it comes to justice, faced with this situation one arrives at a more general question about resources: is today the mere presence of a disorder or disability not enough to ensure participation in the socio-political system? Must the disabled person be able to come up with that bit extra to ensure that the disability is formulated in the 'correct' way? Not to put too fine a point on it, is vigilance needed to prevent the end result of a system that requires an organised formulation of a problem being such that if a sick or disabled person does not command such a presentation, he or she does not exist? The increasing number of diagnosis groups, and the emergence of new initiatives and new forms of power, are to the benefit of disabled people. Counter to this, such developments may be a sign that disabilities and disorders have to be formulated in the manner described in order to 'exist' within the system.

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