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Aspects of studies on the functional impairment electrohypersensitivity

by

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In Sweden, electrohypersensitivity (EHS) is an officially fully recognized functional impairment (i.e., it is not regarded as a disease). Survey studies show that somewhere between 230,000–290,000 Swedish men and women – out of a population of 9,000,000 - report a variety of symtoms when being in contact with electromagnetic field (EMF) sources.

The electrohypersensitive people have their own handicap organization, The Swedish Association for the Electrohypersensitive (http://www.feb.se; the website has an English version). This organization is included in the Swedish Disability Federation (Handikappförbundens SamarbetsOrgan; HSO). HSO is the unison voice of the Swedish disability associations towards the government, the parliament, and national authorities, and is a cooperative body that today consists of 43 national disability organizations (where The Swedish Association for the Electrohypersensitive is 1 of these 43 organizations) with all together about 500,000 individual members. You can read more on http://www.hso.se (the site has an English short version).

Swedish municipalities, of course, have to follow the UN 22 Standard Rules on the equalization of opportunities for people with disabilities (“Standardregler för att tillförsäkra människor med funktionsnedsättning delaktighet och jämlikhet”; about the UN 22 Standard Rules, see website: http://www.un.org; since 2007 they have been upgraded into the UN Convention on Human Rights for Persons with Functional Impairments). All people with disabilities shall, thus, be given the assistance and service they have the right to according to the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (“LSS-lagen”) and the Swedish Social Services Act (“Socialtjänstlagen”). People with disabilities, thus, have many different rights and can get different kinds of support. The purpose of those rights and the support is to give every person the chance to live like everyone else. Everyone who lives in the Swedish municipalities shall be able to lead a normal life and the municipalities must have correct knowledge and be able to reach the people who need support and service. People with disabilities shall be able to get extra support so that they can live, work, study, or do things they enjoy in their free time. The municipalities are responsible for making sure that everyone gets enough support. Everyone shall show respect and remember that such men and women may need individual and different kinds of support.

In Sweden, impairments are viewed from the point of the environment. No human being is in itself impaired, there are instead shortcomings in the environment that cause the impairment (as the lack of ramps for the person in a wheelchair or rooms electrosanitized for the person with electrohypersensitivity). This environment-related impairment view, furthermore, means that even though one does not have a scientifically based complete explanation for the impairment electrohypersensitivity, and in contrast to disagreements in the scientific society, the person with electrohypersensitivity shall always be met in a respectful way and with all necessary support with the goal to eliminate the impairment. This implies that the person with electrohypersensitivity shall have the opportunity to live and work in an electrosanitized environment.

This view can fully be motivated in relation to the present national and international handicap laws and regulations, including the UN 22 Standard Rules/UN Convention and the Swedish action plan for persons with impairments (prop. 1999/2000:79 “Den nationella handlingplanen för handikappolitiken – Från patient till medborgare”). Also, the Human Rights Act in the EU fully applies.

Many people who are electrically hypersensitive in Sweden as well as elsewhere have a living hell today. They are dismissed from their jobs, refused housing adaptation, denied sick leave, compelled to move, etc. While this is happening, a lot of people are talking about the necessity of taking electrohypersensitivity seriously. This talk is not leading to anything since it is action that is required. In the first place, working and housing environments must be created where people who are electrohypersensitive can live and work. The design of our physical, intellectual and social environment is not something laid down in the constitution or divinely ordained. It is not a law of nature that everyone has to have mobile telephones, to use high-frequency lighting apparatus and wireless Internet. However, if someone might say, we have “diversity” in Sweden – surely that applies to everyone? We all listen to our favourite music, dress according to taste, and vote for the party of our choice. But, unfortunately, when it comes to disabilities, adaptation and assimilation generally still take priority over the minority’s right to access – despite the electrically hypersensitive having other needs.

Sweden has officially recognised electrohypersensitivity as a disability. However, a lot of work still has to be carried out by the electrically hypersensitive and their disability organisation, the Swedish Association for the Electrohypersensitive (FEB) to achieve complete equality. Society must recognise in practical applications the right of the electrically hypersensitive to be different, to their distinguishing feature. Society must recognise the right of the electrically hypersensitive to have an equal life in a society based on equality. Treating members of the community equally is not something that should be done as a favour; nor is it something that any parliament or government should politely request other inhabitants to provide others with. Equality is not something to be done “out of the goodness of one’s heart”. It is something one does because it is expected of every citizen, because inaccessibility and discrimination are prohibited by law.

Some doctors and dentists described at an early stage the electrically hypersensitive as “old crones in the throes of the menopause”, “the poorly educated”, “hypochondriacs”, “radiation ladies”, etc. These prejudiced care-providers used these terms despite never having met an electrically hypersensitive person or carrying out research in the field.

At times, the view taken of the electrically hypersensitive resembled a medical pogrom with frightening overtones. Even more frightening is that the situation today, over twenty years later, is and is allowed to be much the same – and not only in Sweden. The entire public debate has been characterised by grand words, commitments and far-reaching promises, which have often been shown to lack the necessary effect. This nonchalance and lack of commitment has per se been particularly insulting. Is all this something that we should be proud about? How much simpler, cheaper and more creditable it would have been to have provided the electrically hypersensitive immediately with the assistance and solidarity that we like to boast about. An immediate decision on a housing adaptation grant, disability allowance, etc.. would have been self-evident. Now we have instead endured almost thirty years of hostilities with big losers, namely the electrically hypersensitive and their next-of-kin.

The electrically hypersensitive must therefore, in every situation and by all available means, demand respect¸ representation and power. They shall very clearly reject all approaches which reflect a mentality of “feeling pity for them” or “caring for them”. Inaccessibility is not a personal problem. It is a problem for society. Inaccessibility is not about attitudes. It is about discrimination. And discriminatory actions and conduct shall not be dealt with by well-meaning talk about treatment. *Discrimination is already illegal!*

The former Swedish Prime Minister Göran Persson has declared that 2010 should be the final target year for the “National Disability Plan Policy” – “From patient to citizen” – adopted in 2000, according to which the whole of Sweden is to be completely adapted to those with disabilities. In addition, there is the EU “Human Rights Act” and the UN “Standard Rules on Equalization of Opportunities for People with Disabilities”, nowadays updated to the UN “Convention on the Rights of Persons with Disabilities”. One of the most important ideas in these documents is the “principle of accessibility” stating that people with disabilities are to have full access to public services. This is the basis for the fast introduction in Sweden and other countries of kneeling buses, wheelchair ramps, hearing loops, automatic door-openers, bevelled pavement edges, etc. However, where are the measures for the electrically hypersensitive? How are they to be able to be a normal part of the community with complete access to council offices, post offices, means of transport, cinemas, restaurants, hospital care and other facilities? Providing every electrically hypersensitive person with individually designed assistance, good care and stimulation to create participation in the community are very responsible tasks that require a high level of skill. Considerably greater demands must be made on training and work supervision than has been the case to date. Sharing experiences between different activities must take place much more smoothly and in a way that is completely free of prestige. The task of medical research must be to increase knowledge about different disabilities, as is in fact clearly defined in the Karolinska Institute’s policy declaration, among other places. The over 200,000 people with the disability electrohypersensitivity in Sweden, as well as all the millions around the world, can only be provided with the right tools by our acquiring knowledge about their disability and immediately putting this knowledge to use to adapt accessibility. Examples of the organisations that have responded to this challenge are TCO Development (Swedish Confederation for Professional Employees), Sif (Swedish Union of Clerical and Technical Employees in Industry) and FEB. *But is everybody prepared to take on this work?*

I have said it many times: It is a true *must* that fully financied, truly independent research projects immediately should be initiated to ascertain the public health. They shall be completely devoid of commercial interests of any sort. This is the responsibility of each elected government in each country, and is of special importance for people with the functional impairment electrohypersensitivity.

We must, here and now, decide how we shall build human bridges of knowledge, for persons with EHS as well as for all future groups asking and begging for our professional assistance. Science, should it be in the form of problem-solving research, or rather a playground for careerists and big industry? Is it the general view of this conference, "EMF and Health – A Global Issue --- Exploring appropriate precautionary approaches", held in London, UK, September 8-9, 2008, that we only shall build half- or ¾-ready bridges...? Or shall we rather build complete bridges…?

People with the disability electrohypersensitivity have an exciting future ahead of them. Work has already started to produce results on a number of these issues, including building construction (cf. Lindberg E-R, Doctoral Dissertation, 2008). However, a lot more can and must be done. There are still many years of hard, constructive and consistent work waiting. I hope that everyone with the functional impairment electrohypersensitivity all over the world can find a common platform for this work, and move the work forward through community and solidarity.

It is now so important for everyone to decide on the continued direction of their activities as well as their focus. A continued energetic action plan for the next few months and years together with a broad collaboration with other disability associations are of the utmost importance here. *There must be an end to nonchalance, lack of consideration, indifference and lack of respect on the part of society. Never accept discriminatory treatment or an insulting special treatment. Stand up for your rights and in this way you'll stand up for everybody's future!*

I would like to conclude by quoting the very wise words of Jan Åberg, a freelance writer in Trollhättan, Sweden, "Everything that happens to us human beings only happens as long as we accept it". *For how long will you accept it?*

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[For additional reading and references to the relevant scientific literature, please, contact the author at <olle.johansson@ki.se>.]