

A case for non-discrimination on grounds of ethnicity in government disability policy

Dr. Adolf Ratzka, Independent Living Institute, Sweden

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Briefly about my background. I have lived and worked in Sweden for 37 years. Prior to that I was living and studying in California for 7 years. I was born in what is today the Czech Republic. After WW II my family, as part of the German minority, was forced to move to Germany. There, at the age of 17 I contracted my disability. Thus, as a person with a disability I have lived in Germany, the United States and Sweden. I might add that in June this year I chose to apply for Swedish citizenship.

In my presentation I will talk about double discrimination on the grounds of disability and ethnic background. My comments are based entirely on my own experience as a person with a disability living as an immigrant in another country.

As a disabled person I am reminded almost every day of the obstacles Swedish society has been building up for its disabled citizens over the centuries, not only in terms of architectural barriers but also in the form of prejudice, preconceived stereotyped notions and infringements of human rights, for example, the right to personal integrity or to free movement. But these forms of discrimination hit most people with a disability living in Sweden and do not differentiate between ethnic Swedes and immigrants. Here, I'd like to talk about the interplay between discrimination on the grounds of disability and ethnicity in Swedish public policy from my own personal experience. Simply put, would the Swedish welfare state treat me differently, if I were an ethnic Swede?

In 1973, while still enrolled at the University of California, I signed the contract to a wheelchair accessible student apartment in Stockholm close to the university where I was planning to do field work for my dissertation. I entered Sweden in 1973 and soon obtained a temporary residence permit as foreign student which I had to renew periodically. My disability was not a factor. Within months I was able to get my social security number and was entitled to health care, in particular, service of my assistive devices such as my ventilator and electric wheelchair. In 1975, my grant money ran out and I could no longer afford to hire personal assistants. So I applied for and received the local government's home helper services. These are community based services where social workers within the City administration send care attendants to help disabled persons with the activities of daily living like getting up in the morning, bathing, going to the toilet, cooking, cleaning and so forth. My temporary residence permit was not an issue.

Upon completion of my Ph D I applied for and received permanent residence that also entitled me to work. That was in the early 1980's, before Sweden joined the European Union. My disability did not play a role. During these years I took night classes at the university and picked up a degree in Psychology. University studies were free of charge for everyone including foreign citizens.

In 1983, I started getting involved in Swedish disability politics. My goal was to improve the municipal home helper services that I together with many thousands

of Swedes received. I started an organization, the first Independent Living organization in Scandinavia. We criticized the services that, as we claimed, made us more dependent instead of more independent. We proposed an alternative in the form of cash payments from the social security system that could be used for the purchase of personal assistance services. At that time I felt that my ideas would have met less resistance, had I been an ethnic Swede.

In 1984, I received a research grant from the Swedish Council for Building Research and obtained a research position at the university. Neither my disability nor my foreign citizenship was an issue.

In 1986, my German girlfriend and I applied for a permanent residence and working permit for her and she moved in with me in Stockholm. My disability was no obstacle for the immigration authorities. In 1994, we applied for the right to adopt a child from abroad. Our German citizenship was not an issue but my disability was. After four years in court we won. Our daughter is now 16 years old.

In 1994, the Swedish Personal Assistance Act came into force which legally entitles people with extensive disabilities to receive direct payments from the social insurance system for the purchase of personal assistance services. The payments are not means-tested, do not depend on family income or property. I qualified right from the beginning. Currently, I receive approximately €180,000 a year for this purpose.

In Sweden, persons with disabilities are entitled to a minor monthly amount from the social insurance system that is to compensate us for the extra costs of living due to the disability. I have been receiving the payment as a result of a bilateral agreement in the social security area between Sweden and Germany. I also got a part-time early retirement pension that was to supplement my income, since it would have been hard for me, on account of my disability, to work full-time. After turning 65 a couple of years ago, I am receiving an old-age retirement pension - very little money, because part-time researchers and activists do not collect many pension points. I am still working part-time as director of the Independent Living Institute.

This past summer, after having lived in Sweden for 37 years, I applied for and was granted Swedish citizenship. It took four weeks to get the papers. In the process my disability was never mentioned. Why did I apply for citizenship if I did not need it for living and working there, did not need it for "importing" wife and child from abroad or for all the benefits that a Swedish person with my disability would have gotten? I applied for citizenship mainly because our daughter wants to be as Swedish as possible. For minors to become citizens at least one of the parents has to be a citizen. Also, now I can vote for friends in the Parliament elections and not just in local and county elections.

I have been living and working in Sweden for 37 years without being a citizen and yet I was entitled to precisely the same services and benefits that Swedish citizens with a disability receive. What have been the consequences for me, my family and friends, my work?

Most likely, if I had been treated differently as a disabled person by Swedish authorities and their policies, without the benefits and services I just enumerated, I would have had a difficult life at least in material terms. Observing differences in quality of life between myself and other persons with disabilities - but with the right papers - might have made me bitter and negative. Also, I often tell relatives

and friends in Germany and elsewhere about my life in Sweden and the benefits I am entitled to which never fails to make a positive impression on them.

Our daughter grew up as the child of immigrants with embarrassing accents who often ask questions and say stupid things. Her loyalty to Sweden, its institutions and people has not been tarnished by hearing her parents complain about Sweden as a country that denied her disabled father benefits that Swedish citizens are entitled to.

In all likelihood, without the benefits and services from Sweden I would not have been able to live there, build a family and contribute to society with my work.

In summing up, Sweden is a nice, small country with many positive features. But Sweden is no paradise, neither for disabled people nor for immigrants. The recent elections have shown that the nationalistic and xenophobic currents that plague a number of European countries are coming to the surface also in Sweden. But all other things equal, my personal experience and conviction is that a policy of non-discrimination on grounds of ethnicity regarding social security and related policies has strong beneficial effects on a country, on the integration of its immigrants, on the cohesion of its inhabitants and on its relationship with its neighboring countries.