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Project STEPS
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Project STEPS - A contribution to the shift between traditions of support

I think that Project STEPS brings up a most important issue in disability support. I would like to bring attention to this, believing it will assist us to move forward. We are used to influence the lives of persons with an intellectual disability by changing the character of services. But services are not neutral, instead they reflect the social role we attribute to persons.

When they are seen as the “Children of God”, the church gets the responsibility for, and gives the character to, support. If we see their disability as a sickness, a medical character is given to support eg. by building an institution like a medical hospital. When we start to recognize that persons have possibilities for development, the developmental model, therapists and trainers gets the upper hand and build, sometimes only rename, services into training-centres. By choosing a social role, consciously or not, we also choose the perspective from which we view what lives are seen as desirable, and thereby what we see as services necessary. The perspective gives the logic to the forms of support to be offered and to the lives to be expected.

But none of these roles mentioned are relevant for Project STEPS. It is when we see persons with an intellectual disability as citizens, members of society, that we expect them to belong and to be part of society and to be able to, with assistance from their representatives, participate in community life like others. They do not need to prove their competence for this participation, as it is a consequence of their right as a citizen. This perspective can be called a citizen perspective or a (human) rights perspective.

When we from a citizen perspective expect full community participation for persons but see how this does not become a reality, because it is sometimes naively hindered or consciously thwarted, we find that these persons are discriminated against. Actions towards emancipation, participation and solidarity becomes three potent avenues to raise their citizenship and thereby to better their lives.

This citizen perspective is a recognized one as regards disability support. The UN standard rules for equalization of opportunities of 1993 is based on this perspective as it talks about “equal rights and obligations” for persons with a disability. When you trace the background to this document you find its roots in the UN position of human rights of 1948. In my own work on Swedish services I found the roots of the change towards community based support in the 1940:s. The motive for the move away from institutions was then expressed as a democratic right for persons with a disability as citizens to use the welfare services organized for the public. Much can be said about this, but an important aspect of this citizen perspective is to see that it is part of a democratic process. Therefore, the move towards democracy in a society becomes the broad background when working for the betterment of lives of persons with an intellectual disability.

With this citizen perspective we also find that this development of disability support emanates in the post world war era. Ideas of democracy, of the establishment of welfare societies, in spite of the poverty of these times, are just some parts of the societal context when a shift starts away from institutionally towards community based services. One cannot find established service models presented at these times. Instead one finds visions of persons with a disability being included in society. Therefore community participation and forms of support contributing to this has its logical roots around 1950.

It was 100 years earlier, around 1850, that residential institutions were established as the response of society to the needs of persons with a disability. Society at this time was under

change as industrialization was on the increase, leaving an old agrarian culture behind. This restructuring of society put new demands on people and during this process some did not meet the new demands. In this way persons with a disability became visible. For those with an intellectual disability the introduction of compulsory education made demands on learning, the nucleus of their disability, which they could not meet. Hence, they were handed over to the new disability services.

At this time services were organized through special institutions. With a variety of institutions, the needs of different groups could be met. There were for example those for “the crippled”, those with a psychiatric problem, the epileptics and “the feeble-minded”, that is those with an intellectual disability. Based on type of disability, persons were sorted and sent to the relevant institution. The deviancy of the person therefore became the source of identification. Common for those with an intellectual disability were their lack of competence to manage their everyday lives. This became reason for society to take care of them, against their will if necessary, excluding them from a life among others. Social exclusion can therefore be said to be coupled with a competence perspective.

In this way one can talk about two traditions of support, an institutional tradition which grew out of the middle of 19th century and a community tradition which emanated during the middle of the 20th century. They are different in their view on the relationship between persons with a disability and society. While exclusion was the idea of the institutional tradition, inclusion into society was characteristic for the community tradition. In spite of this difference, both are logic and natural as they responded to and grew out of the conditions of different societies.

Development away from exclusion towards inclusion into society then becomes a matter of working for a shift between traditions of support. On an individual level the participation and inclusion into community life needs to increase. On an organizational level forms of support needs to be found in community which contributes to participation and inclusion of persons, at the same time as institutionally based services are dissolved. What has been given attention here, through the comments on different perspectives, is the change on a cultural level. A citizen perspective needs to be formed at the same time as a deficiency- or competence perspective needs to be left behind.