

2018

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Recommended Citation

Kokkin Koppe, E. (2018) Representation, Access and Participation for People with Disabilities in Local Government, Universal Design & Higher Education in Transformation Congress, 30th October - 2nd November 2018, Dublin Castle

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Representation, access and participation for people with disabilities in local government in Norway.

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Abstract. Everyone should be considered as citizens and have equal access and right to participate in deliberations over policymaking in matters of importance for ones wellbeing, rights and freedoms. When looking closer into the arrangement of advisory bodies for people with disabilities in Norway, there are reasons to ask if people with disabilities are fully considered as citizens. There may also be a need for a deeper change in the common perception of what it means to have universal human rights and what it means to be included.

Keywords. CRPD, local government, representation, advisory council, universal design, human rights

1. Introduction

After 1948 and the adoption of the Universal Declaration of Human Rights there was little attention to individual rights as such. The focus was mostly on anti-colonialism and collective rights for peoples, like the right to self-determination for indigenous and tribal peoples living in independent states and freedom from colonialism (Moyn, 2010b) p. 85-86.

The awareness regarding individual rights was actually invoked in the 70's. It was President Jimmy Carter who in January 1977 in his inauguration speech proclaimed: "*Because we are free we can never be indifferent to the fate of freedom elsewhere.... Our commitment to human rights must be absolute.*" (Moyn, 2010a)

Universal Human Rights applies to all individuals. However, as a consequence of negative attitudes and approaches to disabled people, the United Nations worked to emphasise that by establishing the Convention on the Rights of Persons with Disabilities (CRPD).

CRPD was adopted in 2006 and was intended to be an instrument for human rights with an explicit social development dimension. CRPD recognises persons with disabilities *as capable of claiming their rights, taking control over their lives and being active members of society.*(UN, 2018a).

Attitudes towards persons with disabilities have before and after the adoption undergone a change from viewing them as "objects" or clients in need of care and charity to seeing them as individuals with rights. But there are still questions remaining how do societies then comply with rights for persons with different kinds of disabilities? Is there a full acceptance that persons with all types of disabilities ought to enjoy all human rights and fundamental freedoms and make decisions for their own

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lives? And are they able to fully enjoy their democratic rights to participate in deliberation and policymaking?

2. CRDP as an instrument for human rights and its influence on politics

In 2001 the Norwegian government published an Official Norwegian Report called “From client to citizen- A strategy for dismantling disability barriers” (Sosial-og_helsedepartementet, 2001). This document highlights areas where the focus is needed on tearing down barriers and thereby empowering people with disabilities to live their lives as citizens who participate and who are included in society on equal terms.

2.1. “Law on Advisory councils on Equality for persons with disabilities”

As a consequence of this historical backdrop, the “Law on Advisory councils on Equality for persons with disabilities” was adopted by the Norwegian government in 2005. The law came into force in 2007 (inkluderingsdepartementet, 2007; likestillingsdepartementet, 2007), but already in 1999 the Ministry of social affairs had encouraged the municipalities and counties to voluntarily establish an advisory body representing people with disabilities. At the time of the adoption of the law, approximately half of all the municipalities and nearly all the counties had an advisory body for persons with disabilities. (Sosialdepartementet, 2005) p. 5.

For the record, all Nordic countries have a similar arrangement for participation and involvement for people with disabilities ((Danmark, 2018); (Island, 2018); (Oy, 2018); (Socialstyrelsen, 2014)).

2.2. The Law as an instrument for participation and social development

The main purpose of the new law was to give people with disabilities an arena where they can participate and deliberate, and by that have an influence on planning in society. The idea is that advice from the councils will contribute to better and more equal access for disabled people. The Council is expected to be involved in all areas that are important to citizens generally like the building sector, transport, housing, kindergarten, education, culture, sports, outdoor life, health, care etc. and thereby strengthening the rights and freedoms of disabled people.

There should not be any limitations as to what areas or issues the Council might involve itself in. The Ministry for Social affairs argument was that participation in planning would safeguard against new barriers, and dismantle and contribute to removing existing barriers. It would therefore, directly and indirectly, fight discrimination of persons with disabilities. Participation and advice should be given at a strategic level.

2.3. Who should be elected to make the Advisory Council balanced and representative?

For the advisory body to be relevant and representative it needs to reflect the diversity in the population when it comes to age, sex, and disabilities.

At the time of the adoption of the law, the ministry could lean on experiences from voluntary councils. The recommendation from the voluntary councils was that there should be representatives from organisations, politicians and the administration. This was considered the best solution by the Ministry, and it recommended this practice to continue.

However, before the regulation, there were five different disabilities that should be represented: reduced mobility, impairment of sight and hearing, learning difficulties and hidden disabilities. This practice was discontinued. The Ministry argued that municipalities had to select members on the basis of which organisations were represented locally. Furthermore, the many "hidden" disabilities cannot be described as one group. In addition, it was the Ministry's opinion that an advisory body also should have representatives from local political parties and the municipal administration. If someone from the administration took a seat in the Council, that person had to be aware of possible conflicts of interest (Sosialdepartementet, 2005) p. 13.

3. Advisory councils in municipalities in Norway as an instrument for ensuring influence and involvement

3.1. Reports show that degree of involvement varies from municipality to municipality.

There are two reports concerning how the councils are functioning in general. The first report is from 2014, published by the Norwegian Institute for Urban and Regional Research NIBER (Niber-report); the second report was published in 2017 by The Norwegian Directorate for Children, Youth and Family Affairs (Bufdir).

3.2. Representation in general

When assembling the Council, the aim should be to make it representative for people with disabilities in the municipality. There are great differences in the challenges faced by people with different types and degrees of physical handicaps, learning difficulties, and other types of disabilities.

There is also a challenge connected to age. The average age of the members of the Advisory Councils is high, and there are very few persons younger than 40 years represented. People under 25 years are more or less not represented at all. On the national level, only 0,8% of the members fit in this group. This fact alone should encourage organisations to motivate their younger members to get involved. Municipal planning is planning for the future! (Bufdir, 2017)p. 12. Not only the organisations, but also the municipalities have to do a job on bringing forward younger people to take seat in the Council. It is all about making the Council representative for the people with disabilities in municipality.

To put the above figures into a perspective, 89% of the members are 40 years old or more. Approximately half of these are 60 years or more (44% of the total). (Bufdir, 2017) p. 12.

The main purpose of the law was to give people with disabilities an arena where they could participate and have an influence in matters important to them. But nearly 2 of 5 members are politicians. The figures are as follows: 38 % in average of all members are politicians, 58 % represent different organisations for people with

disabilities, 4% are others including persons from the administration. (Bufdir, 2017) p. 13.

One argument for electing politicians is that there are two kinds of expertise or knowledge necessary for Advisory Councils. The first kind is the competence and experience that people with disabilities themselves have when it comes to needs, care services and relief measures, solutions and adaptations - that is, what in the Niber-report is called “case-related competence”. (Winsvold, Nørve, Stokstad, & Vestby, 2014) p. 39.

The second kind of competence is the knowledge of organisations and local authority, political systems and political processes, as well as established practices and procedures for academic and political interaction – or what’s defined as a “system and process” competence. This is the kind of competence politicians are supposed to bring to the Council. (Winsvold et al., 2014) p. 39. In my opinion, however, these arguments are more based on an assumption than facts.

Adequate training however can give members of the Advisory Council the kind of “system and process” competence that it is assumed that the politicians bring in. (Winsvold et al., 2014) pp. 40 and 84. Furthermore, there is a risk that politicians by virtue of their experience and role in political life will be given more authority than they should have in the advisory body. This could bind other members who do not have the same experience in expressing their views. (Winsvold et al., 2014) p. 83

It should also be considered that appointed politicians may risk coming into conflict between the political party’s line on matters and the particular view he/she has taken when handling these issues in the advisory body. (Winsvold et al., 2014)

3.3. Competence building

The assembling of an advisory body naturally raises questions related to the purpose, efficiency and working conditions for the advisory body as such.

Based on the purpose of the law, the members of the Advisory Council should receive adequate and relevant training so that the Council can fulfill the role it is supposed to have. Such training and competence building should include knowledge of informal and formal decision making, networking, and more. Newly elected politicians specifically receive training as outlined above.

However, members of the Advisory Council do not always get the same training as the politicians, if they get any at all. The fact is that 2 out of 5 councils had not been offered any training in political work at all (Bufdir, 2018a). One reason for that may be related to when the Advisory Councils are formally elected.

The election of the Advisory Councils will often be done in the second or third meeting for the new city/municipal Council (sometimes even later). At that time, politicians will normally already have received a competence building program that enables them to perform in political work.

“Process and system” competence is not crucial for the council’s role as an advisory body, but it is a great advantage. It will be a challenge for the Advisory Council as such if not all the members receive proper information and training in political work. Lack of process and system competence may affect the level of influence and their ability to participate in planning and to give the municipality relevant advice on time.

3.4. Resources

In order for the council to do its job, it needs to have a good overview of what issues the municipality is working with, who is responsible for cases and where in the decision-making process a case is. It is important that the Advisory Council becomes involved early in the process to ensure that advice given by them can be taken into account.

The Advisory Council is supposed to give advice on matters from many areas. It was the Ministry's opinion that the secretariat should be a part of the Municipal Chief Executive office. This position in the administration is supposed to give a better overview of what was going on in the organisation. (Sosialdepartementet, 2005) p. 13.

The situation is that 1 of 2 secretaries is connected to either the Chief Municipal Executive office (21,8%) or to a political secretariat (33,1%). It's worth noticing that nearly 2 of 10 secretaries are seated in the Department of Healthcare! (Bufdir, 2017) p. 15. The latter may indicate that there still exist preconceptions about disabled people as clients rather than citizens.

Further, 8 of 10 Advisory Councils have a secretary who uses a maximum 10% of his/her time to work for the Council. Only 1% have a secretary that uses more than 30% (Bufdir, 2017) p.14. It is a reason to ask if this reflects the importance and priority given to matters important for disabled people.

Nearly 2 of 10 Advisory Councils do not have a budget at all neither do they have access to economic resources. 4 of 10 have their own budget, the rest have to ask the administration to cover their costs from time to time. (Bufdir, 2017) p. 17. Naturally, this can restrict the Advisory Councils in their work.

Such differences in allocated resources are bound to have an effect on how and in which issues the Councils are able to engage themselves. Universal design, building and houses, outdoor-environments and cases related to healthcare are all high up on the list of cases the Advisory Councils are engaged in. (Winsvold et al., 2014) p 45ff.

On the other hand, the administration according to the intention of the law has a duty to present to the Advisory Council matters of importance for people with disabilities. What kind of cases presented to the advisory body will often depend on what the administration perceives as important for people with disabilities.

4. Hamar municipality's Advisory Council for people with disabilities

In my city, Hamar, the first Advisory Council for people with disabilities was elected and started working in the spring of 2008 (Hamar, 2008).

I have been secretary for the Advisory Council since September 2015. I was appointed to this position before the former Advisory Council left office, and the present one was elected.

4.1. Critique regarding the Advisory Councils working condition

The former Advisory Council had voiced criticism regarding their working condition, more specifically as to how resources were assigned to them. They were not satisfied with their secretary – mostly because the person did not have a sufficiently central role in the administration. To assign me as the secretary for the Advisory Council was therefore an answer to that complaint. My position as legal adviser at the Municipal lawyer's office was accepted.

Formerly, the Advisory Council had no budget, and they argued that a budget would enable them to plan activities better. The present Council is still in a position where they don't have their own budget. Up to present time this situation has not caused any conflicts. There have not been any economic restrictions placed on the Advisory Council's work, and all expenses connected to their activities have been covered. As the situation is at the time being, it is considered unnecessary for the Advisory Council to have its own budget. But that might change.

The former Advisory Council was also dissatisfied with the level of political influence they had. As a remedy to gain more influence, they suggested that two politicians should be elected to take seats in the advisory body instead of only one.

4.2. Representation

The Advisory Council in Hamar has seven members. One is elected among the members of the city board; six are nominated from various organisations. When the new body was formed in 2015, the political candidate was not a sitting member of the City Council. Due to this situation change in the mandate as suggested by the former Advisory Council was discussed.

However, no changes have been made and the question has not been brought back onto the table. The council has six members nominated from different organisations, plus one politician pointed out and elected by the City Council. As secretary to the Advisory Council, I am not a member of the council and have only an administrative role. The sitting Advisory Council has so far focused on other ways to gain influence and participation.

Another issue that has been discussed is how to make the Advisory Council more representative. In 2015, – the average age of the nominated candidates was 65 years. After a request for nomination of younger people, the average age was brought down to 50 years. Distribution in age was as follows: 68+60+48+47+44+31 (the politician, 32 years – is not counted). The Advisory Council did not have any member younger than 31 years after election in 2015. It is also a challenge that people with "hidden" disabilities; such as learning difficulties, etc., are highly underrepresented.

There is a statutory duty to have equal representation of men and woman in public councils. The City Council cannot ignore this rule when it elects the Advisory Council.

4.3. Universal design and equal rights

Increasing awareness of bringing in the Advisory Council early into important processes has been the main focus. Through that, the Council has progressed from being a body that was consulted at the end of the planning process, to becoming involved much earlier in the process. Everyone understands that it is difficult to change something when decisions have already been made.

The Advisory Council should be involved in matters concerning municipal planning. This is about universal design of the future, which includes equal rights to education and work, freedom from poverty, quality of life and happiness.

Process-planning documents state that the participation and involvement of the Advisory Council is mandatory. This requires that routines must be in place to ensure that those who are responsible for handling cases actually involve and meet the advisory body. The purpose is always to establish a dialogue. If the Advisory Council

has something to bring forward, it can be done in the meeting or after the meeting by a written consultation response.

Still, my experience as the secretary, not every department in the municipality is presenting their cases to the Council. In my time there has been few cases related to education, public health, etc. There are departments that do not have a routine for involving the Advisory Council. One of them is the department of city planning. City planning is of great importance when it comes to the welfare, life quality and opportunities for disabled people, so there are still areas to improve in the administration.

On the other hand, the head of the department for healthcare is among those who come to the Advisory Council regularly to inform and seek advice. The same is true for project managers with project related to building construction. In the latter case, there is a formal agreement between the Advisory Council and the municipality administration that the Advisory Council must be consulted in every project regarding building constructions, except for small private houses. The purpose is to ensure that projects are carried out in accordance with the regulations of “Regulations on technical requirements for construction works” (Dibk, 2017)

There has been, and still are more cases where Tek17 can be applied. The minimum requirement as guaranteed by Tek17 is very much something that every construction engineer and architect knows they have to take into account. Universal design in building and construction cases will therefore often be the same as solution required by Tek17.

I can easily understand that the Advisory Council finds cases involving construction of buildings and houses, outdoor environment etc., attractive. These cases are tangible, visual, measurable and easily understood. And there are standards to be applied, like Tek17. Other cases, like participation in municipal planning programs, are more abstract. Participation in municipal planning requires different skills like strategic thinking, argumentation and a strong sense of development and consequences. This way of thinking and arguing may be unfamiliar for some of the members of the advisory body. But training and practice does help to improve!

It has been a common goal to make the Council more visible both among the public and in the municipal administration. To achieve this goal, I helped the Council host a conference with the title “Equal access and participation”. The conference was a success. A very interesting consequence of the conference was that it boosted the members’ self-esteem. The members were proud and happy about the outcome and of the positive feed-back. Moreover, it was a great team-building project.

In the aftermath of the conference, members of the Council have been running a project with the purpose of establishing a pool of electric bikes for lending/renting out to people with special needs. So far, there is a lack of financial funding to cover the cost for investing in such bikes but work is in progress.

4.4. Perception of the Advisory Council

There has been a change in the common perception of the Council. One of my colleagues once said that he could not understand why he had to meet in front of the Council to present his project. The only thing the Council was focusing on, he said, was infrastructure such as guiding lines, contrasts and accessibility for wheelchairs. Maybe it was like that before, and maybe it still is. There will always be room for

improvement, but the Council is more than ever focused on good and including universal design. They are also focused on equal opportunities and participation.

As I see it, during this process, the status of the Council has been changed from being a consultation body in the final phase of a project to becoming a contributing body in municipal planning.

5. Reflection and summing up

If we look to the average standard of living for persons with disabilities and their families, there are reasons to encourage work in society regarding rights and fundamental freedoms for everyone. When the Advisory Council is asking for sustainable and good solutions that gives freedom and equal opportunities for people with disabilities, for instance in building and construction, the answer may well be that what is presented is according to “Regulations on technical requirements for construction works” (Tek17) - which everyone knows, are only minimum solutions. Question for better and more including solutions for people with disabilities will sometimes be met with the objection: “We have a budget and it's too expensive.”

However, there are steady movements toward a better universal design of buildings and environments. And of course, it is of great value in itself that universal design is at the core of the man-made environment because it contributes to removes physical barriers. However, there are still issues that need to be addressed. Issues connected to freedom and rights to education, work, and living standard.

Education increases the likelihood of work and income, but statistics reveal that fewer people with disabilities have higher education than the population in general. Statistics also reveal that persons with disabilities have lower incomes than the population in general. (Bufdir, 2018b). Lack of education and work means a risk of poverty but also of social isolation and less participation.

We also have to address general preconceptions about disabled people. It seems to be the case that disabled people are still viewed more like clients than individuals who are capable of making decisions for their lives based on their free and informed consent as well as being active members of society. (UN, 2018a). Preconceptions are in themselves barriers and prevent equal access and participation. It is, therefore, necessary to argue beyond and above categories to address the way we perceive disabled people. People with disabilities should be viewed as citizens with equal opportunities, rights, and freedoms and that means right to education, work and to live autonomously.

Regarding the advisory body, the authority view on having politicians as members of the advisory body upholds a preconception of people with disabilities as someone who cannot speak for themselves. Indirectly this also upheld a general preconception of people with disabilities as clients, not a citizen who can be able to participate in the deliberative democratic process on their own.

It is maybe useful to keep in mind that politics is a battle over resources – both on a local level and on a national/ international level. However, redistribution of wealth will be necessary to strengthen not only Universal Human Rights but also the special rights and freedoms for persons with disabilities. This obligation to redistribution of wealth may be seen as a moral duty and a consequence of the simple fact that we recognise that there is something we call universal human rights. The CRPD is a mean to an end. And by that follows the argument for a universal designed society. To that

account it can be added according to UN, that universal design is crucial for further economic growth and sustainable development, (UN, 2018b, 2018c). Advisory bodies formed of and for people with disabilities will in the future have to play an important role in deliberation and policymaking for achieving inclusion and equal opportunities and to fight poverty.

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