

Distinguished colleagues and friends around this table, friends of human rights and who wants to contribute to a better life for persons with rare diseases.

My name is Maria Montefusco and i work with disability issues for the Nordic Council of ministers. NCM organizes official policy cooperation in 11 areas. I work primarily with the Disability Council which is an advisory board to all of these policy areas.

Today and since only a few weeks back i can happily say that all countries and autonomous areas within the Nordic region have ratified the UN convention on the rights of persons with disabilities, which is an extremely central document for this event today.

Within the official Nordic cooperation, all work within all sectors, just as within the UN system, need to have an integrated gender perspective. It is seen as traditional for the Nordic region and countries to keep a high profile on gender equality, also within the UN system.

Prior to this work I had the pleasure of working for several years for Rare diseases Sweden which is the national umbrella organisation for at that time 40 rd-organisations. Now for several more. I have also been involved with activities on the European level of RD community.

Today we celebrate the expansion of rare disease cooperation. I feel honored to be here and to be a part of when we start operating within UN structures.

The UN Agenda 2030 slogan "leave no one behind", is a strong message, which should be taken along throughout the whole implementation of the agenda. It should also include persons with demanding health issues and complex disabilities.

I will now mention some aspects of how a rare disease perspective can **visualise what the implementation of goal 5 on gender equality could and should be about.**

I will also argue for a stronger **gender perspective within the global RD cooperation.**

SDG 5 on gender equality is mainly about empowering girls and women socially and economically, and also about ending all forms of gendered discrimination and violence.

Girls and women with rare diseases often have multiple impairments which generate complex disabilities, thereby also complex needs of health care, service and support.

Leaving no one behind in this context is about daring and managing to make this complex analysis, and to see and respond to the needs.

The gender perspective is **quite new within the RD context.** There is very little documented knowledge. But it is no news for us who have been in this work for a while, that there is a relevant gender perspective. There is a lot to learn from civil society and the RD organizations. For example by listening to the testimonies of girls and women with rare diseases and, not least, our mothers.

About girls and women with rare diseases and their mothers, there are both bio/medical and social aspects to bring up. I will mention a few.

- **Discrimination and violence (CRPD art 5 etc)**
- **Right to life – equal response to medical and social needs (CRPD art)**
- **Reproductive rights (CRPD art 6)**
- **Socio- economic rights (CRPD art 28)**

Discrimination and violence (CRPD art 5 etc)

Implementing SDG 5 means making society accessible for all and providing empowering service and support to persons with rare disease and their families

There is documented knowledge that girls and women with disabilities are subjected to challenges within education, labour, reproductive rights, and to a higher extent than others. This goes also for these groups as victims of violence and multiple discrimination.

Living in an institution is the highest risk factor for this group in terms of being victims of violence. Isolation and segregation from mainstream society, dependence on a wide range of individuals, institutions and structures, hinders them to participate equally in society.

Living segregated from mainstream society makes girls and women with disabilities more vulnerable and in terms of risk of becoming victims of discrimination and violence.

Girls and women with rare diseases also compete about getting resources with persons with more common diseases. Resources should be distributed equally and according to need, not according to how common the condition is, the name of the disease or kind of treatment.

Right to life – equal response to medical and social needs (CRPD art)

We need to make sure that international RD development gains girls, boys, women and men and everyone equally.

There is scarce but some studies that point out that men get better and faster care than women.

This male bias in health care systems could be the reason that men also get quicker access to new innovations, technology and medical treatments than women.

There are rare diseases that only affect women, and there is a lack of research on these and whether women with these diseases get equal care in comparison to men with diseases that only affect men.

This is a challenge for the whole health sector, but could perhaps be studied closer within the rare disease field since the patient groups are so small.

On the same topic, some X-bound diseases can have different impact on female/male bodies. These diseases manifest differently on women than on men which complicate the diagnostic process, treatment and care. A study on life quality aspects of women with Fabry's disease show that women with this disease are misbelieved by doctors and other health care personell, not only because of their symtoms differing from male bodied individuals who have the disease but because their symtoms are "female" (fatigue, aches etc). These symtoms are not taken care of with the same urgency as the "male" symtoms. This despite that the disease progress on women goes on unteated, just as it does for men.

Reproductive rights (CRPD art 6)

Healt care, social service and support should be of that kind that anyone can feel happy about bringing children to this world, including persons with health conditions and disabilities.

Attitudes around genetic diseases and disabilities and the probabilities of "passing them forward" brings a great taboo to the issues of reproductive righths for women with rare diseases. Forced or non-consensual sterilization is an extreme form of denying a person her or his reproductive rights which still occurs. Bad enough is arguing against keeping or even trying to have a child. when that is the wish of a woman of adult age.

Socio- economic rights (CRPD art 28)

Implementation of SDG 5 should include a broad variety of girls and women, not least mothers to persons with cronic and rare diseases with complex disabilities.

Persons with rare diseases must be seen as more than patients. A girl or a woman, a boy or a man with a rare disease no matter how complex the disability – is always so much more than the disease. Of course many aspects of RD political agendas are about saving lives through treatments and programmes for better care. We know too little on the situation of this group in educational and job market situations. In these situations though, these persons can not be seen as "RD patients", but as children, students, employees, employers, women, men and having other social roles than being patients.

SDG 5 is about women and men sharing household responsibilities. If families with children with RDs and disabilities don't get the support and service they need, at least one parent will quit their work and this will in most cases be the mother. It is usually the parents and most often the mother who coordinates the life and livelihood of her child, even when the child is an adult. It is also the mother, who leaves her job, and who stays outside the job market. This has both short- and long term consequences on her economy.

Women need to be involved with research

Presence of a women perspective

The RD community, needs to put on gender glasses more often. We will learn more from that and fewer girls and women with and without rare diseases will fall behind.

The implementation of the UN agenda 2030 for sustainable development will be strengthened by bringing in the complex dimensions and cases of rare diseases.