

Norwegian University of Life Sciences Faculty of Landscape and Society Department of Public Health Science

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Exploring the links between the Rights of People with Disabilities and Climate Resilient Development

A Report from a seminar at the Norwegian University of Life Sciences, 18 September 2020

By: Robyn Grøndahl, Siri Eriksen, Ann-Marit Sæbønes



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INTRODUCTION

A discussion meeting of eight researchers, civil society, students and practitioners¹ took place at the Department of Public Health Science, Ås (NMBU) on September 18th 2020 in order to explore the interlinkages between the rights of persons with disabilities and efforts to support climate resilient development. The meeting used techniques for deep inquiry, based on transformational meeting methods (Sharma, 2017).

Climate resilient development concerns how climate action (adaptation and mitigation) can support socially just and inclusive sustainable development. The UN Convention on the Rights of Persons with Disabilities was adopted in 2006 and has 182 ratified parties (UN, 2006). The focus of climate change research and policy has increasingly shifted towards how social and political marginalization produces social vulnerability in the face of environmental change. However, there is a remarkable lack of academic research on how climate change affects persons with disabilities, and even less on how persons with disabilities contribute to building climate resilient development. The seminar aimed to address this shortcoming by identifying how the **rights, vulnerability**, and **resources** of persons with disabilities can help deepen our understanding of how society needs to act and develop in the face of climate change.

This report summarizes the meeting and highlight the points, ideas and questions that emerged during the discussion.

¹ Robyn Grøndahl (Research Student, Department of Sociology and Human Geography, University of Oslo), Siri Eriksen (Professor of Climate and Development, Department of Public Health Science, NMBU), Ann-Marit Sæbønes (Chair, Council on Disability, Oslo), Yngve Bråten (Research Student, Department of Sociology and Human Geography, University of Oslo UiO and associate and senior advisor, Gender Equality and Social Justice, KIT Royal Tropical Institute, Netherlands), Marit Aakvaag (Advisor, Disaster Risk Reduction and Climate Change Adaptation, Save the Children, Norway), Marius Rohdin Karlsen (Advisor, Disability Inclusion, Save the Children, Norway), Ruth-Kjærsti Raanaas (Professor of Public Health, Department of Public Health Science, NMBU), Nikita Amber Abbas (Acting Head, Norwegian Association of Disabled Youth)

2. KEY QUESTIONS ADDRESSED IN THE MEETING

Persons with disabilities are an almost invisible group in climate change research as well as in policy processes directed at achieving the sustainable development. *Climate resilient development* is development that actively uses greenhouse gas emissions reduction measures (mitigation) and measures to adapt to the impacts of climate change to support socially just and inclusive sustainable development (Roy et al., 2018). It is therefore, in part, guided by the globally agreed normative Sustainable Development Goals (SDGs). When the sustainability goals were negotiated, international organizations of persons with disabilities worked to include disability in the sustainability goals, which resulted in the group being mentioned several places in the SDGs. Yet, connections remain weak between work to promote the rights and well-being of persons with disabilities, and climate change and sustainable development actions.

The Intergovernmental Panel on Climate Change Assessment Reports assess existing research regarding the impacts of climate change, vulnerability and adaptation every seven or so years. These reports lay the groundwork for national and international climate politics; however, very little research exists regarding the vulnerability to climate change of persons with disabilities, nor their role in climate action. Persons with disabilities are often presented as vulnerable and hence placed in a victimized position within climate change research and policy. This contributes to the invisibility of disability perspectives in public debates. We need to ask new questions in order to reverse this tendency and understand the role of disabled persons as agents of change:

- 1. In which ways are people excluded from climate change related policy making and decision-making processes?
- 2. How can we redefine "climate resilient development" from the perspective of groups that traditionally are understood as vulnerable, opening up to a plurality of knowledges in addition to climate change "expert knowledge"?
- 3. What will climate resilient development look like from such a rethought perspective; for example, what does climate resilient development look like for a disabled child?
- 4. How can we actively use a framing of persons with disabilities as agents of change within our different arenas of work research, civil society, and practitioners?

3. KEY POINTS FROM THE DISCUSSION

3.1 Language matters

The participants highlighted the power of language. The implications of grouping people as 'disabled people' or 'persons with disabilities' were discussed, and it was pointed out that among organizations working with such issues, the Norwegian colloquial name 'funkiser' is often used. Grouping people as 'disabled' or 'not disabled' is in itself problematic, constituting a socially differentiating and marginalizing process, since all people have different levels of functionality depending on the situation. A grouping of people as 'disabled' mirrors a similar disempowering effect of labelling people as 'vulnerable'. All humans are vulnerable to some extent, and vulnerability is a state which varies with context rather than a personal attribute. A group labelling of people deflects attention away from the knowledge, resources, and capacity that individuals have.

3.2 Attitudes drive marginalization processes

The group discussed the exclusion of persons with disabilities as a root cause of social vulnerability. The discussion highlighted harmful attitudes towards persons with disabilities as driving exclusion, and the need to shift attitudes in order to address marginalization. While most people believe that we should be kind and fair to persons with disabilities, we also have a desire to "not be like them" (disabled), which represents an act of abjection. Words used in everyday life situate a person with disabilities into a person they are not - a stereotype rather than a human being. At the same time, there is the risk of an individual exposed to such attitudes stepping into the stereotyped expected role.

Shifts in attitudes away from stereotyping and abjection are reliant on participation and representation processes. Unfortunately, due to reduced physical and social accessibility, persons with disabilities participate less in public deliberation and decision making than the general public. Therefore, shifting exclusionary processes is likely to take time. Persons with disabilities are diverse, including intellectually disabled, hearing-impaired, blind, wheelchair users, in addition to having other social

characteristics according to gender, age, ethnicity etc. However, they are often excluded from civil society movements, such as the women's movement. Increased participation by persons with disabilities in research and politics is vital for the inclusion in society in general. Hence, knowledge of CRPD is important among policy makers and researchers working on climate resilient development.

3.3 The question is not "why include the disabled", but "why are the disabled not included"?

The workshop participants furthermore reflected on how to enable participation and representation. Interest groups, committees, and researchers need to actively reach out to persons with disabilities. Traditionally, persons with disabilities have had to fight to ensure that they are included in decision-making processes. However, rather than asking why persons with disabilities need to be included, we should be asking why persons with disabilities are *not* included. When someone is not included, they are in reality actively excluded. This illustrates why it is important to be aware of *how* we see a problem, and indeed *what* problems we see at all.

The workshop discussion stressed the importance of real representation, including direct representation in processes by organizations of persons with disabilities themselves, instead of representation by people who speak on behalf of the disabled. At the same time, we must also bear in mind the "tyranny of participation", a type of participation for participation's sake without real impact. Furthermore, it is important to reflect on what the one who is present in a room or forum to represent disabled people is exposed to in terms of harmful attitudes or reactions. Several participants emphasized that persons with disabilities are the experts on their situation, the marginalization processes that they face, and know what knowledge and capacity that they can contribute to climate resilient and other societal development processes.

The workshop discussion critiqued the consequences of the narrow epistemologies and ontologies that have been reproduced in research and politics. Representation and participation by persons with disabilities in research projects may help shift such

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epistemologies. In particular, the workshop participants stressed the importance of respecting the lived experiences of persons with disabilities as worthy knowledge.

3.4 Experience from past work shows the importance of real representation

There is inspiration to be drawn from other movements such as the Fridays for Futurestrikes arranged by youth. This civil disobedience action is carried out by an age group that is often not heard, but that is now mobilizing globally. It has managed to push the agenda, demonstrating that change is possible. A question was raised regarding the extent to which young persons with disabilities have formed a part of this movement.

Climate change and major disasters are leading to more disabilities. For example, cyclones lead to physical damage, while hunger and famine lead to developmental disorders. Save the Children works extensively internationally with disaster prevention, minimizing the extent of disasters and preparing children and their communities for disaster. In their activities, Save the Children can improve their focus on disabilities and avoid reproducing attitudes that label people as 'vulnerable'.

Experience from practical works shows that when children are included, they contribute a lot of intellectual resources and provide complementary perspectives to those of adults. An example is represented by a child's concern regarding the height of a railing in a new building, a perspective that most likely would be ignored by an adult. Children are a diverse group that have a potentially important voice. Critically, NGOs that work with community development, such as Save the Children, can now apply to the Climate Fund. This provides a funding opportunity for expanding work on climate change adaptation and persons with disabilities. In addition to funding, a key challenge in including perspectives of persons with disabilities has related to the need to balance between structured planning of activities in advance of a practical project, and being responsive to perspectives and changes as the project is being carried out. Identifying effective forms of participation may be important to best bring out the 'invisible' voices in a community, regardless of degree of (dis)ability. Save the Children's work revolves around the key goal of children's participation and the right to express themselves. A lesson from this work is that children must be involved at all stages of an intervention in order to achieve inclusion and participation; participation must permeate project development from planning to evaluation.

3.5 The importance of overcoming the many daily, invisible barriers to representation and participation

The workshop participants highlighted that it is important for actors within climate change and development (NGO, civil society, research, policy makers) to reach out; children and young persons with disabilities face many challenges in everyday life that other young people do not have to think about, such as applying for assistive products to improve their daily functioning and independence, such as wheelchairs and hearing aids, and attend medical appointments. Many small barriers to carry out daily activities take a lot of time and energy. Reaching young persons with disabilities is often perceived by societal actors as a much bigger struggle than reaching out to youth in general, even though in essence it is the same as reaching out to any other youth. Therefore, persons with disabilities must often fight more than other youth to ensure they are included. Disabled youth are often innovative and persistent in finding unique solutions to ensure their own participation.

The participants suggested that establishing a Youth Council with explicit focus on climate change and disabilities could help achieve representation and participation. This suggestion addresses the question why disabled people are not included. Such exclusion is related to people's attitudes, so a key priority is to discuss why we tolerate disabled people *not* being on committees, youth councils, etc. Exclusion is systematic and we need to explore why this is so. The participants recounted the lived experiences of exclusion: as a young person with a disability, you have more than enough to deal with in your life, including being met with prejudices and resultant fears of exposing yourself too much. You must be strong to fight to include yourself in daily interactions and decision-making processes.

The following statement from one of the participants illustrates how understanding of inclusion must shift: **"Youth with disabilities do not have different needs from other youth: We just need different solutions to meet the same needs."** This observation forms the core of redefining climate resilient development from a social justice perspective – giving space to understanding and ensuring people's needs through socially contextualized and different solutions defined through representation and deliberation.

3.6 In what arenas can we start to make a difference quickly?

The workshop discussion started to identify some practical ways in which a shifting of attitudes and understanding of inclusion can take place: teaching activities at NMBU, for example, can draw on empirical cases with a focus on persons with disabilities. Such an explicit focus can also be included in student term paper topics or MSc theses. Research-practitioner networks can be strengthened to ensure inclusion of disabled people's organization. Research projects should actively involve participants with disabilities, preferably in research/advisory roles and not just as informants.

The student participants at the meeting suggested that they could more actively discuss topics related to disability with fellow students. Issues surrounding disability and the rights of persons with disabilities are often of great relevance to social science research, and in particular the research topic that students are interested in pursuing in their thesis. Yet it is seldom a topic that they are trained to think about.

There are many ways to start making a difference within the NGO sector. For example, Save the Children has many arenas and actors where disability perspectives can be more actively promoted; for example, among donors who contribute financially such as individuals, supporters, and large institutional donors; with colleagues in Norway; within the Save the Children organization itself and in collaborative activities with other NGOs; and in dialogues with civil society organizations, states, and municipalities. Unfortunately, there is often a lack of time and a lack of good advice on these matters. Often it is through engaging in specific practical projects (which require funding and time investment) that deeper knowledge about topics can be gained.

3.7 What does it take for real participation to take place?

Two key limitations to real participation by persons with disabilities in knowledge and decision-making processes, including in the arenas identified above, concern time and language. It is important that research, civil society, students and practitioners work explicitly to identify ways to overcome these limitations. First, in most arenas, we seldom spend enough time in bringing in citizen perspectives and reaching out to people. Deadlines limit inclusion. There are also research ethics challenges involved in including children with disabilities in research. It is perceived as difficult to include the group within the time frame of a (research) project. Second, language can be very exclusive, particularly within research and policy. Save the Children has attempted to write reports in different formats with children as the target group. Such adjusting of language and presentations may help information reach groups not often heard or included.

A concluding observation made at the workshop was that it is critical to discuss the topic of disability consistently within *all* activities, as a way of "spreading the word" and making persons with disabilities a natural part of all contexts rather than invited participants in selected processes. It needs to be a priority within research, civil society and policy making alike to talk more about the rights and knowledges of people with disabilities and make persons with disabilities a natural part of all activities and processes.

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