**Nothing about us without… who? Disability rights organisations, representation and collaborative governance**

**| © Julia Bahner**

**Plain English Summary**

**1. Introduction**

The idea for this research project came from 11 different disability rights organisations in the region of Västra Götaland, Sweden. The 11 organisations were represented in a group called the Council on Disability Issues. In this Council they discussed things that were important to disabled people’s lives. In the Council there were also politicians and officials whose job it was to listen to disabled people and try to realise their ideas. For example, it could be about accessibility problems when going to the doctor or taking the tram. In the research project, the 11 organisations wanted to learn about how their group could work better and how they could have more influence in regional politics. They also wanted to know more about disability rights organisations that were not in the group. A starting point for the project was Article 4:3 in the UN Convention on the Rights of Persons with Disabilities (CRPD). It states that disability organisations should have a say in decisions about disabled people.

**2. Summary of the research approach**

I started this research with reading documents about the Council on Disability Issues. The regional administration had many rules about how the Council should work. Some of the rules had changed over the years. I interviewed officials and politicians about the rules and why they had changed. I also asked them about things that they found difficult to deal with in the Council. Then I gathered the disability rights organisations from the Council for a group interview. We discussed how they thought their work in the Council went, if something was difficult and what they wanted to change. Finally, I interviewed 22 different disability rights organisations that were not part of the Council. I asked them what they knew about the Council and if they wanted to be part of it or not.

**3. Summary of the main points in the paper**

A common theme in the documents and in all of the interviews was that there were many different ideas about what disability is and what a disability rights organization is. In the policy documents, the idea was that a disability rights organization must be organized in a certain way, otherwise they could not get support from the region, or be part of the Council on Disability Issues. The politicians discussed that it was difficult to help all disabled people because sometimes their needs clashed with each other. A similar question was discussed by disability rights groups. It was sometimes difficult for them to collaborate when they had different views. Some groups did not see themselves as disabled people but as patients of healthcare. Others wanted to be part of feminist activism or do activism through art e.g. dance.

**3. Summary of the main implications**

It can be seen as unfair that only a certain type of disability rights organisation can be part of the Council on Disability Issues. Disabled people may have many good reasons for not being a member of such organisations, but still their voices should be heard. It also should not matter how disability rights organisations define themselves because they can still have good ideas. I believe that it would help collaborations between disability organisations and with politicians if the focus was more on ideas, than on identities. The current system for the Council on Disability Issues needs to change for it to be more inclusive. In the future, I hope that there is no need for a special Council like that. Instead, disabled people could work together with non-disabled people who are also struggling with different things in their lives. Then everyone who is discriminated or doesn't feel included in society can be part of groups there to decide how society should improve.

**4. More information**

Julia thanks the disability organisations for coming up with that idea for this project and for taking the time to be interviewed. She also thanks all the people who gave suggestions throughout her work with this paper.