

**Identifying options for developing new EU policies to promote active citizenship for people with disabilities – a European stakeholder perspective**

Proposals within the framework of the DISCIT project “Making people with disabilities full citizens”

**Participation in change**

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**Additional notes**

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## The place and consequences of personal experience in research

Looking at and researching disability issues is far from being a neutral activity and, as in the case of DISCIT, when the people with disabilities take an active part in the research, all the stakeholders have to consider their own and personal relationships along with their probable future needs for personal assistance and/or technical aids. The citizenship of people with disabilities is not only external and observable but also personal and structural.

The personal experience of researchers has an influence on each of their outputs, as is more or less the case in all human activities, sometimes by adding a particular value to the product and sometimes by making it worse. Some practices have incorporated the personal dimension of the researchers in the process, such as psychoanalysts who consider it a factor to overcome or some therapists who use it as a tool of understanding.

One objective of this paper is to express some initial comments on the impact of the personal experience of living with disabilities on the research process, and in particular in DISCIT. Looking at how the experiences of people with disabilities can contribute to the implementation of the CRPD, an observable fact is that the presence and the contribution of partners with disabilities at all levels of the research induces a sort of obligation for all to “*think the body loose*”<sup>(1)</sup>, a learning strategy that is an obligation for people with disabilities but which is not taught either to children or to adults with or without disabilities.

In other words, the **participation of DISCIT stakeholders identified as “people with disabilities” introduces a new variable** that should be taken into account, and if the stakeholders with disabilities have had several occasions to elaborate their experiences through writing and oral presentations, that should encourage all the stakeholders to consider the following questions: What are my experiences and my representations of disablement? How do I understand it and what are the answers I could recommend to me, to my peers and to the community? This exercise will enable everyone to understand that there are not two classes of people, one with disabilities and another without, that everyone has different abilities and different assistance needs, that some restrictions and barriers can be removed and others cannot, that personal assistance is a human service with rules and which is manageable by the showing of respect to each other.

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<sup>1</sup> Pierre Dufour, presentation of the research « *La pairémulation: une fonction sociale émergente ?* » « *Peer counselors: an emerging social role – moving towards a system for qualification and certification* », 2014

It is easily understandable that the answers of an interviewee would be different if he/she perceives that the interviewer has a similar experience to hers, and in the same way an interviewer with personal experience of discrimination on the basis of his/her personal aptitudes, or who has had to negotiate personal supports to be independent will automatically introduce parameters like empathy or knowledge that will impact the content of the interviews.

Many researchers with visible disabilities who conduct research on disability issues have also had the unpleasant experience of being told by their university tutors that they are “*too close to the object of their research*” to produce scientific results, an accusation that parents and people with non-visible limitations do not face. When parents are collaborating with the researchers as professionals, they have two advantages: the first is to fully benefit from their abilities and their potential, and the second is the possibility to hide their proximity to the object of the research, or at least argue that there is distance when there is not. The other stakeholders also have their personal histories and their experiences that influence their approach, although no one asks them to be different than they are. The fact is that when personal experience is visible and perceived, it creates specific interactions and influences relationships.

The structural points related to the personal experiences questions the conditions of equality between the stakeholders (irrespective of their abilities). It also questions some choices made during the research process and in particular the conduct of interviews, as well as the selection of the stakeholders, organizational matters relating to meetings and the procedures of information sharing.

### **The question of classification**

The redundant issue of any research on disability concerns groups and categories. Do people with disabilities have to be considered as a separate group? Can people with disabilities be classified by groups? We claim here that this approach is a cul de sac, that considering people with disabilities as a separate group cannot be in anyone's interests. By way of illustration let us look at the legal wording of the treaties against discrimination, like the Amsterdam treaty and the CRPD.

In the Amsterdam Treaty, the EU states are committed to taking “*appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual*

*orientation*”<sup>(2)</sup>, and in the CRPD preamble, the States’ parties recognize that “*discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person*”<sup>(3)</sup>, and define the discrimination on the basis of disability as “*any distinction, exclusion or restriction on the basis of disability ...*”<sup>(4)</sup>

The problem with this formulation is that it is not coherent with the definition and that it focuses on what is not rather than on what exists. The definition in the CRPD recalls, “*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*”<sup>(5)</sup> If the disability movement is satisfied with the new paradigm that defines disability as an interaction between the environment and the “*impairment*”, the concept of the discrimination “*on the basis of a disability*” looks insane under this definition and not coherent with CRPD principles themselves. In other words, the formulation that prohibits “*discrimination against any person on the basis of disability*” prohibits the discrimination of discriminated people, a “category” of citizens grouped around the discrimination they suffer. If those citizens are not discriminated against, will they be still disabled or will they become only impaired?

In addition, “*to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation*” as the Amsterdam Treaty affirms, is to consider people with disability as the only specified group of people linked by a feature that needs to be defined. So even in the core of the treaties they have obtained, people with disabilities are excluded among the excluded by being the only persons defined by what they have not, abilities, and a negative characteristic, the impairment. People can be proud of their characteristics, of their sexual or ethnic identity, of their religion or belief, of their age or sexual orientation, but the state of the abilities is not an identity that concerns only some people and not others.

After thinking about this issue for more than 10 years, we are convinced that the proper way to formulate it cannot be based on disability but, on the contrary, on abilities. **Any discrimination on the basis of physical or mental capabilities is illegal, regardless of the abilities and irrespective of the barriers.** Human capabilities do not have to be defined and this formulation does not create

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<sup>2</sup> [Treaty of Amsterdam amending the Treaty on European Union](#), Treaties establishing the European Communities and certain related acts, as signed in Amsterdam on 2 October 1997

<sup>3</sup> [Convention on the Rights of Persons with Disabilities](#), Preamble, item h).

<sup>4</sup> [Convention on the Rights of Persons with Disabilities](#), Article 2 - Definitions

<sup>5</sup> [Convention on the Rights of Persons with Disabilities](#), [Article 1 - Purpose](#)

any separation between able and disabled people: any human being has the right to access, those who walk as well as those who do not and use a wheelchair or a walking stick, those who are guided by a dog or a personal assistant, those who read with their eyes as well as those who read with their fingers, with a reader or with a computer ... This is clear, it is not contestable and it is obviously easier to apply than the current formulation that is based on what is not. It is based on everyone's capabilities and easily understandable, it does not need a definition and considers all human beings to be equal, whatever their abilities.

A summary of the ideas in this paper might appear at first glance to show a sort of contradiction, because after having started by saying that there are crucial differences between those who have the experience of living with disabilities and those who imagine the consequences of living with disabilities, we affirm that there are no categories of people separated on the basis of their abilities and inabilities. In fact, there is no contradiction but just a different approach, one discriminating against people on the basis of their abilities and the other on the basis of their experience, the first focusing on what is lost in regard to a norm and the second focusing on what is learned from personal experience.

The consequences of this shift are far-reaching; it not only offers the easiest way to implement the rights with a formulation that concerns everyone, whatever his or her abilities and not only a part of the population with particular rights. It also offers an appropriate way to implement the CRPD by using an inclusive wording, which prepares the global society to live with the growing part of the population that is becoming "differently able".

The current formulation develops assistance services in the following way:

Disabilities -----> Needs -----> Assistance

Our proposal encourages everyone to valorize the experiences of people with disabilities and is the challenge which is at the core of the DISCIT project and which focuses on how to tap the knowledge based on personal experience:

Experience -----> Knowledge -----> Contribution

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