

**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

A short study by Jean-Luc Simon

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Participation and citizenship

Before presenting proposals for action, it is necessary to define the meaning of participation as understood by people with disabilities themselves and in the context of the social actions in which they are involved. What do the three aspects of participation - "*political citizenship (right to vote and be elected), civil citizenship (inter alia, right to access justice) and social citizenship (right to adhere to trade unions, associations, or right to benefits)*"⁽¹⁾ – mean for people with disabilities? These are the objectives and goals of an ideal citizenship in a perfect world free of discrimination, but in fact before achieving this level of “perfect” or “theoretical citizenship”, **people with disabilities have to claim their place and create the conditions of equal citizenship**. The Convention on the Rights of Persons with Disabilities (CRPD) is the most advanced tool they have obtained to date from the international community in order to achieve citizenship, a tool which they have actively contributed to build. However, the CRPD is still not fully implemented and the conditions of equal citizenship are not yet met. This is, to varying degrees, the case everywhere.

Even if we, the people with disabilities, have access to voting and have the right to be elected; even if we have the same rights as human beings and equal citizens, and even if we are active members of associations and Disabled People’s Organizations (DPOs), we still face barriers everywhere. This is why the implementation of the CRPD is requested and needed before we can imagine becoming equal citizens who have severe restrictions of their personal capacities in a highly competitive world.

This document is based on the understanding and expectations of people with disabilities. For this reason the participation of people with disabilities has to be viewed in the context of implementing the CRPD more as a tool of understanding than an objective to be attained.

¹ Discrimination Generated by the Intersection of Gender and Disability (European Parliament, 2013: p.39)
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The objective of this participation is not one-sided, but aims to learn from both individual and collective experience in order to build a **common European culture of personal support**.

Practical participation

It has been frequently observed that users of services often come up with different solutions than the people who assist them or the providers of such services. And, indeed, there is no reason not to look at both experiences, one motivated by **the desire to receive adapted supports** and the other by **the desire to provide adapted supports**. The slogan "*nothing about us without us*" is still valid and has to be effective not only at the decision-making tables but also at all stages of implementation. And if the last 20 years has seen the implementation of **political participation** by the DPOs and leaders, it is now time to prepare a long-term action plan to implement **practical participation in making the CRPD a reality**.

This practical participation is needed to identify:

1. **Resources** of people and community,
2. New ways to **facilitate** the use and expression of these resources, i.e.
which ones can be used and how.
3. Best ways to **implement** and disseminate these resources in the most comprehensive manner.

Practical participation means that people with experience of living with disabilities must be empowered and trained to give understandable information to the stakeholders directly and not only through their representative DPOs. Eight years after the United Nations has adopted the CRPD and three years after it has been ratified by the European Union, the current situation of the DPOs makes a large number of them unable to build the necessary partnerships needed to implement the CRPD. Created with the objective to provide adapted services or to gain recognition for the Human Rights of people with disabilities, the success of their political lobbying has committed the state and the entire society to develop and manage services they will create and lead, Now that the Human Rights of the people they represent are recognized, the DPOs are going through a sort of identity crisis and are having to change radically their ways of working, their manner of organization and their funding models. The arena of their activities has become a market and one of the first consequences of their success has been to change the role they have to play into a competitive one, for which they are not prepared. At the same time **more and more institutions and organizations call for expertise and**

invite people with disabilities to give advice, train people and to provide expertise in the context of their new obligations to implement the CRPD.

This situation generates numerous problems:

1. There is no coordination between the people with disabilities who are invited and intervene.
2. To live with disabilities does not automatically bestow a special competence to be a trainer or an adviser.
3. People with disabilities are considered only as witnesses and it is still difficult for them to establish equal partnerships.
4. People with disabilities who receive a pension or some form of social welfare have few opportunities to be paid for their work because such payment can result in the reduction or the termination of their pension or social welfare benefit. .

Recommended initiatives

On the basis of the previous short analysis, we propose to share first proposals for initiatives at the EU level within the framework of the 6 competency domains of the Commission, i.e. Accessibility – Participation - Equality - Employment - Education and Training - Social Protection and Health. The first of these proposed initiatives obviously concerns participation and applies across all the above domains.

Beyond citizenship, in the context of the implementation of the CRPD, participation has to be precisely described and defined **as well as the privileged tool for its implementation**, and people with disabilities must be supported and empowered to identify, elaborate and transfer their knowledge. The reality in many European countries, if not all, is that the heart of the principles adopted with all sincerity by the UN as a result of the pressure of the world community of disabled people, that is to say, the participation of people with disabilities is still not engaged with sufficient will and concrete collaborations. Those citizens who have direct experience of the kind of exclusion and discrimination that has to be fought and stopped, those citizens who have this lived experience are the primary experts, and by definition the only people who know what they need and what they want.

Like any human being we, the people with disabilities, need more support than others for basic and vital functioning, but **we don't want to be embedded in the social representations of our carers**

and in what they believe about our needs, even if the latter are motivated by sincere feelings or a healthy solidarity. We need support, but like any social actor we also need to contribute, to provide support, in one word to participate. We, the people with disabilities, cannot only receive and what we receive has no sense if we don't have the opportunity to **engrave our humanity in the exchange** of knowledge and services.

Research on participation and participation in research

In order to build and implement solutions it is vital to capitalize on the diversity of the knowledge that people with disabilities have built up. The way that leads to identifying the solutions that will reduce the negative consequences of the restriction of our abilities is not only difficult and subtle; it is an emotional space and a maze in which meetings between needs and satisfactory solutions for all the stakeholders need highly elaborated strategies.

The experience and knowledge that are lacking today in the new players of inclusion such as schools, enterprises, administrations, trades, civil organizations ... are primarily in the hands of those who are restricted in their abilities. How are these key players involved? How are their experiences collected? How can knowledge be extracted and expertise built on the basis of these experiences? How are people trained to identify and communicate their needs for assistance? How are new actors in the field of inclusion in education, health, employment, planning ... trained? How can the experiences of the people with disabilities who live independently help to build the expected aging European society?

Before citizenship can be achieved, the **participation of people with experience** of living with disabilities **at all stages of the process from the beginning to the end** needs to be clearly reaffirmed and supported. It must be specified here that this proposal is not motivated by any desire to construct a "specific space" or to say that only people with disabilities have competencies in these domains. On the contrary we would love to convince everyone that there is an urgent need **to collect the knowledge of users, to organize it and to make it understandable and transferable**. This way of analysing a situation from the user point of view and transferring the knowledge elaborated by the users themselves has several positive consequences; it gives the people that are usually seen only as beneficiaries a role to play; it encourages partnerships to be offered to the participants and the opportunity to enrich their learning with concrete collaboration; and it changes the role of the partners, for the carer is being helped to understand by those he/ she usually supports.

It would be necessary to develop research programmes to collect and classify this knowledge, but there is also a need for messages to be sent to the EU member States to encourage them to adopt such inclusive approaches as soon as possible.

As I write these lines, the *French National Council of Disabled People*⁽²⁾ has approved a French draft Decree that redefines the mission of the *National Observatory on training, research and innovation on disability*⁽³⁾ and at no place in this text is there a mention of **the contribution that people with disabilities can make. Instead the Decree will take the experience of participation restrictions and discrimination in this field of research.** Even after the Circular sent by the French Prime Minister to all Ministries on 4 September 2012 on the inclusion of disability in bills, the DPOs drew attention to the CRPD and the Circular was amended. However, but the nomination of a contingent of people with experience of living with disabilities was rejected out of hand.

This example comes from the country where this author lives, and it would be interesting to have studies on **how the data on participation** of people with disabilities **are collected in the EU** countries, and on the rules and procedures of such partnerships between people with disabilities and the other stakeholders as well as on **how their experiences contribute to the CRPD implementation** at all levels. Examples of the practical participation of people with disabilities in implementing the CRPD need to be identified, collected and evaluated, like the recent initiative of the National Solidarity Fund for Autonomy in France “to affirm citizenship for all ... build together policies that affect us”⁽⁴⁾.

The disability movement itself should be encouraged to evaluate the participation levels and practices in their own operation, to reflect on their successes and their failures, cost and benefits; this applies in particular to those who are also providing services. The few volunteers of the DPOs that do not provide services mobilize so much energy and support, that too few of them can summon the capacity to be at the table to participate in the rhythms of decision-making meetings or bring the necessary rigour to bear on the decision-making process.

Identifying, training and using trainers.

The second priority concerns the development of Human Resources and the best way to identify, train and use trainers with disabilities in coherent ways of working with common rules and

² Conseil National des Personnes Handicapées -CNCPh-

³ Observatoire National sur la Formation, la Recherche et l'Innovation sur le Handicap -ONFRIH-

⁴ Caisse nationale de solidarité pour l'autonomie des personnes âgées et des personnes handicapées, April 25th 2014
http://www.cnsa.fr/article.php3?id_article=1336

procedures. Several EU competency domains are concerned, but to identify the potential trainers it would be necessary to elaborate and develop an initial work programme with the DPOs.

Training needs are numerous and various, and the time has come to launch a policy rooted in the experience of the citizens concerned that finds its strength in their desire for change and their creative talents. But prior to forming this we need a vision based on the experience of Independent Living and on the lessons learned from the assistance relationships, with the objectives of **strengthening individual capacities, developing resources and enhancing the potential of both the caregivers and those being helped.**

Discussions with authorities are becoming more and more technical, and the people who can give an analysis based on their own experience or that of the members of the DPOs they represent have to read, understand, analyse, summarize, consult, amend, advise, train, educate ... and to intervene in a range of different domains. In addition, there are also a lot of situations, e.g. accessibility, where the interests of the stakeholders are in conflict. In relation to discussions among the members of the French National Council of People with Disabilities on new laws and strategies for accessibility, a volunteer with a disability and a high level of knowledge and expertise says "*he deplores the deficit of technical competencies of a large part of the DPOs representatives*"⁵.

Here, too, the collection of examples based on *practical participation* would be necessary. It would permit us to understand **what are the added values** of what the French call the *quality of use*⁽⁶⁾, and would also give some insight into the practices developed by professionals with disabilities⁽⁷⁾.

A better understanding of the processes that motivate the participation of people with disabilities, would not only greatly facilitate the implementation of the CRPD and open up citizenship to people with disabilities, but it would also permit the collection of data and knowledge on the learning processes, on the peer-to-peer virtues and limitations and it would in general enhance citizenship and a « *full and effective participation in society on an equal basis with others* »⁽⁸⁾, for all, whatever his or her abilities.

⁵ Christian François, Delegate of ANPIHM <http://www.anpihm.fr/> and Vie Autonome France coordination-handicap-autonomie.com/

⁶ Qualité d'usage : <http://www.certu.fr/qualite-d-usage-r50.html>

⁷ Some of the founders of HANDIGO have personal experiences: <http://www.handigo.com/lagence/parcours/>

⁸ The European Disability Strategy 2010-2020 (COM(2010) 636 final)

Call for actions

1. Initiate and implement a **European conference of the experts of use** in the disability area.
2. Adopt a clear priority that encourages and **supports the participation** of people with disabilities **in the implementation of the CRPD**.
3. **Define the areas of participation** with rules and procedures.
4. **Collect and list examples of practical participation** in the context of the implementation of the CRPD, and identify best practice.
5. **Fund research programmes** to establish and underpin the concept of the **quality of use** as well as the knowledge coming from practice and its transferability.
6. **Elaborate repositories** for the training and practice of the expertise of use.
7. Create European **levels recognition** of the experts of use.
8. **Collect and list the training needs for the professional** branches of education, health, human resources, trading, bank & insurance, transport, planning, tourism, architecture ...
9. Define and adopt a European **professional status of expert of use**.