DPI Europe

A network of active European citizens for the Implementation of the UN Convention for the Rights of the People with Disabilities

Activity report
2015-2016

Adopted by the Regional Assembly
Zagreb, Croatia, October 16th 2016

Dublin, Ireland, the 23 February 2013, at the EDF General Assembly, the last time the DPI Europe Officers met with Frank Mulcahy who passed away on July 15th 2015.
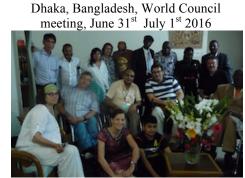
Rest in Peace Franck

DPI Europe Activity report

2015-2016

These 2 last years of activities were full of unexpected events and unplanned works. Indeed, due the international context paved of terrorist attacks, wars and refugee flows DPI Europe was solicited on new tasks related to the **Disaster Preparedness** and **migrants with disabilities** with the EUR-OPA program of the Council of Europe.

Indeed, due the autocratic and disrespectful DPI management, the Regional Chairs from Africa, Arab Nation, Asia and Europe met in Istanbul on January 2015 to discuss and plan a foreseeable future for the Organization. The result their work is summarized in the Istanbul Declaration[1] and DPI Europe was charged to assure the temporary Headquarter and the financial management of the global organization. The main decision taken in Istanbul was to organize an extraordinary World Council meeting hosted by DPI Bangladesh, BPKS, from June 29th to July 1st. The results were the adoption of a statement to withdraw the past Chair and the election of an interim committee charged to lead DPI until the next world assembly.[2]

Dhaka, Bangladesh, World Council meeting, June 31st July 1st 2016

"These last three days were rich, full and empty of good discussions with a lot of seriousness, respect and listening to the others; the DPI we love."
A participant

The 9th DPI World Assembly was organized on March 21, 2016, in Cairo, Egypt[3], and new Executive Committee Members were elected.[4]

We, persons with disability from all over the World have called for the empowerment of all marginalized people; we called for participation in all political offices to ensure that our voice is heard; we called upon those who oppose the practice of hate, discrimination and oppression; and we recognize that sustainability requires greater equality.

Cairo, 21 March 2016, a tribune of the 9th DPI world Assembly

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[1] **Annexes 1:** Istanbul Declaration
[2] **Annexes 2:** Dhaka Statement
[3] **Annexes 3:** Final declaration of the 9th DPI World Assembly
[4] **Rachel Kachaje**, Malawi, Chairperson, **Dinah Radke**, Germany, Vice Chair for Under represented Groups, **Nawaf Kabbara**, Lebanon, Vice Chair for for Human Rights, **Jean Luc Simon**, France, Secretary, **Shoji Nakanishi**, Japan, Treasurer.
Special Advisors: **Kalle Konkkola**, Finland, Refugees and Humanitarian Crisis. **Lehbouss El Id**, Mauritania for information.

At the European level, DPI has contributed to a range of papers submitted to the European Institutions or in the frame of the research DISCIT[5].

Today, the world is facing multiple crisis, human conflict and natural disasters may strike anywhere at any time and throws millions of people on the roads of exile, and In this world undergoing turbulence our beloved DPI has to overcome a conflict of governance which impede its development and threatens its existence. Despite its meager resources, DPI Europe played a major role in the reorganization of the world organization these 2 last years and will have to work hard again in the near future.

The foundations are laid, but the damages of the past presidency are multiples and so important that a large part of the organization has to be rebuilt from the beginning, not identical but inspired by the same principles of mutual support, respect of each other, dignity, democracy, transparency and mutual confidence.

Being united is a priority to obtain the effective and concrete application of the CRPD and this unity could be not obtained without any respect of these principles, we need to confront our opinions, to express our voices and to debate, we must discuss, create alliances, sometimes to be opposed, but never to be divided.

21st Croatian Symposium of Persons with Disabilities, Zagreb, an initiative of a DPI Europe Member

Our Nations, our communities and our families need us as much as we need them, and because living with disabilities requires the crossing of series of crises and to face the unexpected at any time day and night, **our experience of the crisis management is a tank of knowledge more useful than ever**.

The Human Rights profile of a monitoring system in relation with the DPI Europe capacity will be developed to reach the followings goals:

> *Discussion with different stakeholders*
> *Selection of appropriate useful partners*
> *Development with public and International Institutions*
> *Participation in national and international conferences and meetings*
> *Engagement in different research projects*
> *Clarify And augment the number of DPI-Europe members*

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[5] **Annexes 4:** Pages 6 to 13 of this document

Activity report
2015-2016

Annexes

Annex 1

<div align="center">

DPI Europe Activity report
2015-2016

Agenda & main contributions

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A. **27 January 2015: OING Conference of the Council of Europe,** Strasbourg, France
   a. <u>Democracy, Social Cohesion and Global Challenges Committee</u>
B. **31 January 01 February 2015:** Istanbul Turkey
   a. Meeting of the DPI Regionals Chairpersons (Africa, Arab, Asia & Europe)
   b. Global coordination of DPI IRP (Inter Regional Platform), head Office.
C. **30-31 May 2015:** Warsaw, Poland
   a. **EDF AGA**
   b. **DPI Europe** Executive meeting
D. **21 May 2015:** Brussels, Belgium
   a. **"Disability and Disaster Preparedness – Toolkit Release"** Council of Europe Office.
E. **28-30 June 2015:** Dhaka, Bangladesh
   a. **DPI extraordinary World Council** meeting hosted by BPKS
F. **18 June 2015:** www.
   a. Opening of the <u>DPI Facebook</u>
G. **14 August 2015:** www.
   a. Opening of the <u>DPI web site</u>
H. **10-11 March 2016:** Aix-en-Provence, France
   a. 3rd meeting of the **Working Group on migrants, asylum seekers and refugees** in the context of major risks prevention and management
I. **18-21 March 2016:** Cairo, Egypt
   a. 9th **DPI World Assembly**
J. **21-22 May 2016:** Dublin
   a. **EDF AGA**
K. **28-31 August 2016:** Davos, Switzerland.
   a. "**Integrative Risk Management-towards resilient cities**" Annexes 5

Written contributions:

I. **2014-1015:**
   a. **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.** Annexes P.
II. **23 September 2015:**
   a. Comments and proposals to a paper on the article 15 of the European Social Charter in the light of the CRPD (Annexes)
III. **23 May 2016:**
   a. **DPI Europe Comments & Amendment proposals** on the Council of Europe Disability Strategy 2017-2023 (Annexes)
IV. **12 July 2016:**
   a. Note of intent: **Why people with disabilities have to be embedded in the SDGs (Annexes 5)**

Annex 2

ARTICLE 15 IN THE LIGHT OF THE UN CONVENTION ON THE RIGHTS 0F PERSONS WITH DISABILITIES

Comments by DPI Europe

Underlined
DPI-Europe comments

"*Article 1 Purpose*
The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of <u>all</u> *human rights and fundamental freedoms,* by <u>all</u> persons with disabilities *and to promote respect for their inherent dignity.*
Comments: This formulation is a problem because it implies that there are people with disabilities and people without, it creates categories among citizens. In addition, it obliges to state who is considered disabled and who is not. The wording I have adopted and which I promote is "*by all whatever personal abilities*" For me the change of this wording is a long-term objective to reach. At last, the right wording is "by all", but when it's needed to identify and compensate specific needs, "whatever personal abilities" has for me a lot of positive impacts. It neutralizes the situation and, first and more important, it don't create categories of people.

<u>The second precision</u> deals with the difficult issue of defining persons with disabilities. It is usually said that social policies need to have a definition of the group of population they are dealing with; now this has proved to be definitely impossible as person's can't be defined but only described. The Convention therefore, in its first article, writes a description telling who the persons are for whom this Convention has been adopted.
Comment: This is a key point. It's impossible to identify and create groups on the basis on disability.

"*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 the society on an equal basis with others*".
Comment: This definition is a bit ambiguous could also means that persons with *long-term physical, mental, intellectual or sensory impairments* who enjoy full participation on an equal basis are not person with disabilities, that would be a mistake.

This description makes it clear that disability is to be considered as the result of the interaction between the person's impairment and the barriers that this person may face in everyday life.
Comments: To my understanding, the result of this interaction is not disability but discrimination when there are barriers, and inclusion when it's accessible and useable.
It would be useful to have a mention in the appendix of the ESC or in an interpretative observation on the broad description of the group of persons with disabilities to be considered especially in article 15, and in general, for a good implementation of all articles.
Comments: we are just citizens with particular needs, not a group, not separate, not a part, but people excluded by the psycho/socio and environmental barriers. I think we can only speak about a proportion of the population, a percentage, a rate of peoples disadvantaged in certain situations, but not on the basis of groups.

There is no shared definition of inclusion. Is it being on the list of enrolment or is it really attending school on a daily basis? Is it being in the same building, in a special classroom with other students with disabilities, or is it being in the classroom with the other students?

Comments: I don't think we need a definition of "inclusion" in its general meaning, but may be definition of what is an "inclusive education" would be easier to achieve. I think also that inclusion alone could be a damage when equality and security are not assured.

Addition on the Paragraph 1 on Education

The states must engage their ministries for education to build inclusive education systems and engage a medium term action plan to transform the special education systems to support the inclusive education. Initiatives must be taken to implement peer counseling and peer support programs all long the educational courses.

Addition to the paragraph 2 on Employment

It must be recalled that public institutions must employ peoples with disabilities by direct employment and/or by buying services to sheltered workshops.

We wan also ask to the Council of Europe to look on the negative effects of the allocation systems shifts when a person who receive allocation and compensation related to a disability earns a salaries or any kind of revenues from a professional activity.

Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;"

Comment: How people with disabilities can change place of living? What are their rights to get the same level of support in the new country they choose to live?

General comments

The council of Europe has a great opportunity to evaluate the level of the access of People with disabilities to their Human Rights by comparing the situation in countries members of the EU which sign ratify the CRPD with the countries that have not ratify. Are people with disabilities in Nederland, that has signed but not ratify the CRPD, more discriminated than in Germany or Romania that have ratify it with the additional protocol? How the Council of Europe can encourage the Belarus and Tajikistan to sign?

The Conference of INGOs of the Council of Europe is an adapted place to publicize the CRPD within the European NGOs and a plan of action could be elaborated in that objective to see how the European civil society can seize the disabled people inclusive participation in their programs, practices and internal functioning.

Annex 3

Council of Europe Disability Strategy 2017-202
DPI Europe Comments & Amendment proposals:

Green, DPI Europe
Brown, Original
Blue, EDF

Introduction
Page 4: Addition of a point

With the objective to mainstream the CRPD principles and goals in their internal rules and to enforce it at all levels of their own operations and projects, organizations of the civil society should be supported to partnerships with disabled people's organizations and to employ workers with disabilities within their employees.

Education and training
Page 9:
Replace the last sentence of the first paragraph
"*This includes education for everyone about disability and persons with disabilities, their rights, qualities and needs*,"
with
This includes education for everyone on Human Rights and disabilities

Page 10:
Addition of a fifth item as follow:
To implement the necessarily ambitious education and training programs that are needed to implement the CRPD, trainers, experts and peer councilors with personal experience of living with disabilities should be certified and networked.

Equality and non-discrimination
Page 10: Council of Europe bodies, member States and other relevant actors should seek to:
Addition to the second item
Support efforts to collect adequately disaggregated data and targeted statistics on discrimination and inequalities factors towards persons with disabilities and include this information in general statistics and data collection.

Addition in the second paragraph from the EDF proposal
… the development of training and communication initiatives targeting a broad range of persons with disabilities and of professionals, including civil servants and service providers.

Accessibility
Page 15, last paragraph, Item 44, Addition
It should therefore be viewed as an investment that will positively contribute to the inclusion of persons with disabilities in all aspects of society and that will facilitate the entire life of all citizens and their access to education, communication, trade, job and independent living.

Page 16, item 46
Replace … no one is excluded » by « no one is left behind »

Freedom from exploitation, violence and abuse
Page 21, Addition of an item
❖ *Strongly encourage national and local governments to develop empowerment curriculums that will develop awareness and the self-protection of people with disabilities.*

Annex 4

Participation in change
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"
A short study by Jean-Luc Simon, DPI Europe Chairperson
September 2014

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)*"**(6)** – 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. The implementation of the CRPD is requested and needed before we become equal citizens in the today's highly competitive world.

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.

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**.

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[6] [Discrimination Generated by the Intersection of Gender and Disability](#) (European Parliament, 2013: p.39)

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 usually supported.

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**.

The *French National Council of Disabled People*[7] has approved a French draft Decree that redefines the mission of the *National Observatory on training, research and innovation on disability*[8] 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.

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[7] Conseil National des Personnes Handicapées -CNCPH-
[8] Observatoire National sur la Formation, la Recherche et l'Innovation sur le Handicap -ONFRIH-

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"[9].

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 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 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 people.**

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*"[10]. 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*[11]**,** and would also give some insight into the practices developed by professionals with disabilities[12].

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* »[13], for all, whatever his or her abilities.

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[9] Caisse nationale de solidarité pour l'autonomie des personnes âgées et des personnes handicapées, April 25th 2014.
[10] Christian François, Delegate of ANPIHM http://www.anpihm.fr/ and Vie Autonome France coordination-handicap-autonomie.com/
[11] Qualité d'usage : http://www.certu.fr/qualite-d-usage-r50.html
[12] Some of the founders of HANDIGO have personal experiences: http://www.handigo.com/lagence/parcours/
[13] 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**.

Annex 5

Additional notes

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*"[14], 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.

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

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[14] 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

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*"[15], 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*"[16], and define the discrimination on the basis of disability as "*any distinction, exclusion or restriction on the basis of disability …*"[17]

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.*"[18] 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

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[15] 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

[16] Convention on the Rights of Persons with Disabilities, Preamble, item h).

[17] Convention on the Rights of Persons with Disabilities, Article 2 - Definitions

[18] Convention on the Rights of Persons with Disabilities, Article 1 - Purpose

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 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

Annex 6

Why people with disabilities have to be embedded in the SDGs
Note of intent 12/07/2016

Referring to the exclusion note of the "*First Circular on the Tentative Draft Program*" of the invitation to joint the Open SDGclub.Berlin, hosted by the German Council for Sustainable Development and Co-hosts on November 21 till 26, 2016, what are expected are practical examples and proposals.

As disabled people' global NGO, Disabled Peoples' International can show a range of benefits coming from our contributions, as people with disabilities;

- Because what is usable for us is easily usable for all,

- Because the specific barriers we need to overcome uncovers new and unknown ways to go, to move or to make,

- Because the experiences living with disabilities develops new perspectives and reveal unknown human potentials,

- Because what people with disabilities have learned from their living experiences is what the entire world have to learn, i.e. Make more with less, economize, evaluate and regulate the energy, find alternative ways to reach, listen, see, feel and communicate, be creative and prepared for the unexpected.

The objective of the Open SDGclub.Berlin is to "*to help participants to better understand what they can do and to expand their options*", and people with disabilities have a lot "*to share to blend lessons, and to follow up with what we collectively find would help us make our case*."

References:

In essence there are two flavors regarding disability in the 2030 documents fixing and prevention and bettering social situation, and especially around technology question is what disability image shapes action.

We published on robots and negative impact on employment of disabled people a discussion that is not happening. http://www.mdpi.com/2075-4698/6/2/15/pdf

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Annex 7

The Cairo Declaration
March 21, 2016

We, people with disabilities and disabled people's organizations (DPOs) representing 66 countries from around the world, have participated in the international conference titled United Nations Convention on the Rights of People with Disabilities (CRPD) and the Sustainable Development Goals (SDG) – "No one left behind" organized by the Arab Organization of Persons with Disabilities (AOPD) in partnership with Disabled People's International (DPI).

We extend our appreciation for the welcome and support received from the Egyptian Government who generously hosted this international conference.

A special thank you to the Arab Organization of Person with Disabilities (AOPD) for organizing this conference. DPI welcomed regional organizations representing persons of disabilities from all over the world, including RIADIS Latin America, ADF in Africa and PDF in Asia pacific region, which contributed to the success of the conference.

This conference, in part, is a celebration of DPI's 35th anniversary and the opportunity to host DPI's 9th World Assembly. But most importantly the world is commemorating 10 years of the adoption of the first Human Right Treaty of the 21st Century, the Convention on the Rights of Persons with Disabilities (CRPD), which has been ratified by 162 States, which represent 84% of the United Nations (UN) members.

However, we express our concern that ten years after the CRPD, some governments in the world have not ratified the Convention. Furthermore in a majority of countries, the charity and medical paradigms are still the dominant philosophies adopted to engage with disabilities issues. Persons with disabilities in these countries are not treated as equal citizens, and we recognize that society must restructure itself, culturally and physically to meet the demands.

After the adoption by the United Nations General Assembly of the 2030 Sustainable Development agenda in 2015, we, people with disabilities, from all over the world, gathered here, in Cairo, Egypt, in high appreciation that the world is finally considering disability as a Human Rights issue, and is including persons with disabilities in the 2030 sustainable development agendas, actions and processes.

The 2030 sustainable development agenda includes disability in 7 of the 169 agreed upon targets. This has been the result of the efforts of the global disability community, however, we strongly believe that disability related issues must be included in most of the targets, in particular those related to the alleviation of poverty.

Recognizing that 15% of the world's population is fitting the description of disability as outlined in te CRPD, we also recognize that many more human beings will fall under the CRPD definition of disability in their lifetime; this means that disability is an ordinary condition of life and that policies that benefit the target group of the CRPD benefits nearly all seven (7) billion people that habitat the world sometime in their life.

Today we all focus our efforts on ensuring that the indicators of the 2030 sustainable development agenda include the concerns of people with disabilities. In particular we feel that questions related to health care, inclusive education, employment, independent living, social protection schemes, and accessibility should highly consider persons with disabilities.

We recognize that science, technology and innovative development cycles are ever shorter and are influencing the success of the 2030 agenda; disabled people and others acknowledge that problems related to science, technology and innovation development are not limited to disabled people not having access to related products and developments, but also can exhibit other problems such as changing perceptions of expectations of people that can also hurt disabled people.

Acknowledging further that many of the governance discussions are happening in an anticipatory way, meaning at the conceptual stage of science, technology and innovation developments; we believe that a way must be found that allows disabled people to be part of science, technology and innovation governance discourses at all stages, in a meaningful and continuous way so that disabled people can react to and advise on emerging issues.

The world in general, and in particular the Arab world, is facing a major humanitarian crisis resulting from war and conflict. It is the position of the conferees that violence and wars will only bring more disaster, destruction and human misery. It is our belief that we, as human beings have the means and tools to communicate with each other, and to put our common goals for a peaceful and just world, in front of our particular interests and egoism, and to use many available peaceful conflict resolution tools to deal with differences and confrontation.

With all the conventions and treaties signed and adopted thus far concerning the Human Rights of the citizens of the World, the international response to different humanitarian crisis including the current situations faced by the Arab Region are far from meeting the minimum required measures and criteria that meet the basic human rights for all humanity. Ten years after the CRPD, different humanitarian interventions still need to have a better understanding of the needs of refugees with disabilities and to remember all those victims with disabilities who cannot travel and escape.

Based on the above, Disabled People's International (DPI), the Arab Organizations of Persons with Disability (AOPD), RIADIS, Pacific Disability Forum (PDF), and African Disability Forum (ADF), representing people with disabilities worldwide, call upon all human rights activists and organizations to join together in solidarity with people with disabilities including refugees, women and children, and aboriginal persons who live in constant violation of their basic human rights. DPI, AOPD, RIADIS ADF, and PDF call upon all members, supporters and partners to join hands and fight discrimination, marginalization, and abuse, in every aspect.

We, persons with disability from all over the World who have met in Cairo, call for the empowerment of all marginalized people; we call for participation in all political offices to ensure that our voice is heard; we call upon those who oppose the practice of hate, discrimination and oppression; and to adopt the language of humanity that unites human beings. We recognize that sustainability requires greater equality.

The Universal Declaration of Human Rights, adopted by the UN in 1948, clearly states that "all human beings are born free and equal in rights and dignity". Let us all work together for a world that knows how to respect the dignity for all humanity regardless of any differences. Let us all join hands to fight poverty, pollution, mismanagement of resources and lack of justice. Let us work for a world that respects everyone as free conscious human beings.

We call on the disability movements and human rights organizations to unite and place our common interests for equality and non-discrimination at the forefront of their agenda. We call upon all United Nation agencies to apply inclusion in their programs, and to consider persons with disabilities as major participants in the development of their programs with a strategy based on our philosophy and practice "nothing for us without us".

We call for the empowerment of people with disabilities and for their full participation in the social and political life of their countries and their local communities.