

Miguel Carbelleda Pineiro – President ONCE & ONCE foundation

Luis Cayo Pérez Bueno – President CERMI

Yannis Vardakastanis – President EDF: 1997 protest in Amsterdam nondiscrimination article in Amsterdam union. Term disability disappeared. 2007 1 milj for disability. 2010 ratification CRPD. 2015 first review of the EU by CRPD committee in Geneva. European accessibility act. 2015 deliver act. Last month disappointing internal market committee. Adopt a very important resolution. Products en services and good accessible. Campaign is on. Will see what will happen middle of june!

First commissioner (Thyssen) that came twice. Leave your positive legacy. New decade. Commission start preparing European disability rights! Need term rights. 2020-2030. Not to victimize most vulnerable in society. European rights agenda. 2021 second European year of pmh. Stay united & more inclusive. NOOZO is not a slogan, it is a way of live, a demand discrimination 15% population cannot be tolerated.

Luca Jahier – President Group III, European economic and social committee (ESC). : (painter El Greco.) CRPD first UN convention to be ratified UN. Disability movement: values, rights, people and sustainable development.

European Commission: European pillar of social rights. Social dimension 2025. Good step in good direction. Potential to reach out to all europ citizens. Universal access to all services, quality employment, income support. Hope this will become binding. Not enough: Social investment, social innovation. Protect rights. Link europ pillar & 2030 UN agenda/Europ agenda for sustainable development. Link is missing. Pillar only Eurozone country. ¼ of existing provisions speaks about social rights . make pillar a success and enlarge it.

Share common goals, shared responsibility. Being active in civil society, taking position. Political position.

Spanish government representative: keep building Europe. CERMI public-private cooperation

Marianne Thyssen – European Commissioner for Employment, Social Affairs, Skills and Labour Market. Commission: halve way, presented many of the main initiatives promised. What counts is agrees on these and have results. Presented social package, social pillar. You are All co-authors on social chapter. EU and all member states part of convention. Takes time to translate convention on the ground. Commission committed to do its part. Ex. :

- Core priority: promote the right of free movement of all people in EU; do not lose your social protection when you move. Modernize. Proposal long time care benefits in cross boarder situation can claim rights. Pilot project on European disability card 8 countries. Raises interest. 2018 evaluation and next steps, feedback of members in participation countries.
- Promotion of Independent Living. Home care & community based services in pillar of social rights.
- Accessibility: web access. Directive. Agreement on measures to implement Marrakesh treaty.

- ⇒ European Accessibility Act is necessary! Inclusive Europe: accessibility cannot be optional! Discussion not easy. International markets. Active involvement will remain essential for the discussions. We have to work together !

30% pmh at risks of poverty or social exclusion in EU.

26 of april proposed **European pillar of social rights**

- ⇒ Will serve as a compass for reforms. Convergence in Europe. Investing in people and enable to fully participate in economy and society. Needed competitive eco and sustainability of our welfare systems.
- ⇒ Specific principles inclusions, work environment adapted to people's needs,...
- ⇒ Many tools not in EU hands. High level endorsement of pillar in November. All member states can participate.
- ⇒ Initiative work-life balance for working parents and carers. Dependent relatives 5 days of paid leave per year right to request flexible working arrangements. Accessible, affordable and quality formal care services.

Count on constructive fb. Pillar & reflection paper on the social dimension as part of the 5 contributions Junker in white paper.

#### **AGA Business session.**

Rodolfo: secretary

#### **Financial issues**

Gisèle: goed werk, profond. Dépenses d'assurance attention les frais réel. Aandacht hebben voor alle kosten.

Catherine: not certain financement for next year.

Yanis: working on our proposal. Make demand social dimension EU. Hope commission except this. Budget for the organization is approved every year.

Adoption of final activity report 2016

Has to be detailed, transparent. Ppt. everything normally already in general communication.

#### **European Accessibility Act**

Published by europa commission. Pos response but wanted the act to be stronger. Discussion going on in council. In internal market committee in the parliament. Council & parliament to strengthen the act. Demonstration.

Report adopted by committee proposes to weaken the act (not take in account EDF suggestions) parliament not very ambitious. Week 13<sup>th</sup> june discussion in Strasbourg (plenary). Amendments

needed to the report. Reflect strong position of parliament on the act. Monday meeting of council. Tomorrow finalized relation, letter to member states. Letter to send to your MEP's. they are sensitive about public opinion. Send letter to parliament and you government.

Not open, didn't vote for us on 1<sup>st</sup> December

- EPP
- Alder group (liberals)
- ECR

Discuss with disability inter group.

### **Emma Placencia from European commission**

Act:

Clear def. what accessibility is. Art. 9 of convention. Intention is not to implement all of it. A large part for which we have common rules for the internal market. Internal market.

All economic cooperators you product and services need these requirements. Match supply with demand. Obligations for private sector, obligations to buy and spend for public sector (=2 legs).

Systems needed to make sure obligations are complied with.

- Declare it: trust
- Market surveillance authorities: checks
- Complaints administrative procedures & in court

Standards. If you fulfil requirements reward you can place products, services anywhere in Europ.

Penalties when there is no compliance

1,5 Y discussions member states, 1y with parliament.

Discussion:

Obligations to public authorities: which exo operators are being concerned (also small one,...) timeline orientations.

Article: safeguards from disproportionate bargain and fundamental obligation: report it, document is, asses it.

- ⇒ Safeguard not a loophole
- ⇒ Not meant to be implementation a la carte
- ⇒ To reinforce proportionality of proposal.

2y to implement in national laws, 4y to bmake law applicalbel. Timeline that is proposed.

Other piece of legislation. Anti-discrimination. Art 19 directive. General obligation is not accessibility act

Wes accessibility directive = is not the same complements accessibility act.

### **Marie info about available tools.**

Points at risk:

- Obligations on to public authorities.
- Certain companies will be excluded. Small companies.
- List of products and services that commission proposed, is cut. Demand include buildings.

Toolkit also available in electronic version on website + sended by email. Tools for social media.

Example of tweets ad member you would like to target. Everyone can do it. Not online organizations also personal example.

Advice on how to involve media, strongest weapon. Advantage to industry lobby we can do it open out in media industry not .

Publications with basic information in all languages.

Organize a public event: demonstration, or a sit in, flash mob,... anything that brings visibility. Media is attracted if you give them a nice image. If you need anything let us know.

Questions:

- Jeanpiero: Article 9 but article 19 I can live where I want. Cost. Money health services. Cost to remove barriers. Services need to be accessible. Is a condition to be a citizen of EU.
- Thorkild: we focus on industrial people. They are afraid. Sat down with them and showed them what they could do, able to do. Aim discussions also to industry. And then to politicians, we have to vote in 2019 and will remember them.
- Albert: suggestion. Augmenter l'économie Européenne. Convaincre société civile. Aspect positive economic.
- Yanis: commission is better ally than the people in parliament we elected. Cannot understand they Can vote against the people that voted for them. They have to listen to us not to the industry.
- European union of the deaf: transport is covered. Languages and communication needs to be addressed as well. Right freedom of expression and right of transport.
- Nadia: if it doesn't take into account all of art 9 what will be the aim of the act that makes us as other European citizens.
- Jean-luc: critique d'industriel: contre la complexion des toutes règles, critique contre Europe. Stratégie contre ce critique.
- Dulal Bangladesh : UN disability champion 2012. Act not just applicable in EU, also global implication? EU supports developing countries. Should be incorporated. Garments. Embassy in different countries. Possible to incorporate it. Motivation.
- Gisèle: action a notre MEP. Coordonner correctement pour avoir de plus d'effet.

- Christina : importance of the confrontation with industrial sector. Potential for the industry. Information on this would be very helpful on the national level
- Marcel: Act is for everybody, benefit for all. Not small minorities. Access also to work, need to have access to good education. Access to have access to good services speech text,.... Miss in the title 1 word: inclusion. When we talk about work, safety at workplace.
- Psychologie: art 9 eliminations of barriers and obstacles = deinstitutionalisation: institutionalization is a barrier, not building, barrier to the outside world is a barrier for us. Prisons, migrants,... access to services and information on equal basis. So that they can access services and information. Persons under guardianship who lose legal capacity to do so.
- Branislav:
- Special guest from Asia: in the investment of EU countries in Asian economic frameworks.
  - ⇒ All comments today included, we will receive text tomorrow. Time pressure, need text on Monday.
  - ⇒ Draft text we can send to industry, not create miss information.

Emma: Responses comments on EU:

- Concrete ex. let us know.
- Summary of impact assessment. If we do it together costs can be reduced by half.

## Results elections

### Anniversary of disability movement

Donata - autism Europe: last period of vice presidency.

2 keynote: 1. Yanis, 2. Duran Lopeze (CREMI)

1. In 2021, 22 years as president. Last time as a candidate. Preparing the organization for the transition. Prepare for leadership in 4 years. Be transparent about it.

1997 preparing constitution, independent working group EDF. March 1997 first general assembly. We speak about general, horizontal issues. Was not like that in the beginning, cultural change. Disability movement was theoretical concept, today it exists. Work at local, regional, national level, more inclusive, transparent, democratic, more representative. CRPD not knowledge of the few, we need to make it the real instrument of every person with disability to achieve change. Change is not political neutral. EDF sit not be the organization to seek compromise, should be the organization to say yes or no. human rights organization, be able to protect rights of PmH. Real independent voice of pmh, but with very strong intern consultations. Strength: way we decide in our organizations. More space for women pmh, young pmh, refugees, need more intensive support. Before we ask others to be more inclusive, we have to look inside! Look how inclusive we are. Seek alliances. Mainstream disability issues.

2. Art 13 great achievement. Madrid declaration 15y ago. Hope AGA will elect a new version of this declaration. We need to visibilities disability. 16% pmh in Europe (just under the population of Germany). Socio-economic changes have an impact. 60<sup>th</sup> anniversary of Europe. Children: Study in mainstream schools with support they need. Still many challenges. Report how to promote innovative strategies. Crisis, sad period. Should help us to regain new strength, push forward with innovation. Forces us to bring new responses, need for change. Social basis for the social sector. New model based on result. Can only achieved if we are united. Nondiscrimination = key principal. Pmh not a means to make profit. Competitive advantage. Stress the importance of private funding threw CSR. Realistic models, social innovation, open models. Diversity as innovative value. New forms of volunteering, new types of activism (way young people engage has changed). We are the biggest donor in the world??

### Round table

1. Ana Pelaez Narvaez: representative
2. Helga Stevens
3. Bede Sheppard: deputy director of children's rights division of human rights watch.
4. Rodolfo: moderator

4. Messages of important institutions. More than 10y waiting for directive: nondiscrimination directive. Since 2008 sleeping somewhere, was forgotten. This morning we got clear explanation how European parliament in particular commission has more or less killed European accessibility act. A number 1 member in European parliament, how is it possible to vote against it is for people and not for industry.

Ask 2. From European parliament a perspective on 20y. she is member of conservative group, is 1 of the groups who voted against. Thank you for very good report on concluding observations. European disability strategy.

2. America 1990 Americans for disability act. Amsterdam treaty word 'disability' appeared. But still a lot of work to do, very much behind. Not moved forward. Very frustrating. Some positive movement ahead. Eur. Parliament: most diverse: 2 deaf, wheel chair, visual, 6 that identify themselves as disabled. Possibly more. Better than some national parliaments. CRPD positive step. Made colleagues much more aware, need to implement this in our work. Different committees (I am member of justice and homeland affairs for fundamental rights) does not come up in these committees. It does in Social an work affairs. But it is not limited to this. All committees should be aware of disability issues. Diss. Act: I am disappointed. However I believe there are Some problems and management problems from the start. Another MEP should have taken this on. They are not aware of disability issues. Contact your MEP more than 700. Follow up. They don't know what it means. There will be a vote in the internal market. Hope there will be amendments, need to be better, improved, if not it will not be compliance

with CNPD. European charter of fundamental rights, prohibits discrimination on basis of disability. Employment. In Belgium: Unions don't know a lot about disabled workers.

1. Work together. 173 countries have ratified the convention. Because of our organizations,... Did exemplary work. What is left to be done? Most significant part. Go ahead in f-difficult way. Have to believe that rights of all pmh and all rights are the same, they have to be implemented. Questions are not obvious even not in our own organizations. (right to vote, women with disabilities to have children, to make own choices,...). No one should be left behind: women, children, pmh, different sexual orientation, poor people, non-visible disabilities,... people we don't reach with our organizations.

3. because of children's rights an CRPD we are able to talk about the issues, we got the right terms now to talk about it. Division network on pmh. They should not be responsible on all of our work on pmh. Children's division, women's, refugees, sex,... should all think about how it relates to pmh. Better represent, defend include pmh.

Questions:

- Jean Pierre: how can we transfer our work to the young generation. EDF history.
- Cerebral palsy Europe:
- Guide dog federation: petition better access. Blind people cannot use the European website.
- Albert: veel mensen hebben gestemd voor de Franse presidentskandidaat die tegen het Europese project is.
- Klaus: horrible orphanages big part pmh. In eastern Europe! Can you give us some more info about this. EDF wants to support
- Marica: MEP not aware about diss issues, how should we train them?
- Maureen – inclusion Europe: panel, AGA 2027 what positive change they would like to found?

Answer:

Helga: Train colleagues by not voting for them. 2027 fully accessible, catch up with US. Accessible website Europ. Parliament: surprised, we need to set the example before we preach to the member states. Follow up on 2 levels: European and national level.

Ana: discrimination in addition to using tool, use the optional protocol. We barely talk about it! Some countries have not ratified the protocol. So we have a support system. CRPD well known, but mostly to us, those who are working in the disability movement. They don't feel they also need to work about it. We can have everyone engage in it. Need to make a huge effort to renew the movement, need to include young people, so they can become leaders. Instrumental barriers, the languages. Support to young pmh. Support to participate in Erasmus programs,...

Bede: Serbia, Armenia, Croatia,... what can we do about it? Countries want to join the EU in the future. Africa & Asia. Receive large amounts of help from countries European agencies, how can we make diss. A priority for development providing organizations. To encourage change exclusion from schools because of pmh: all children have access to mainstream schools if that is what they choose.

Yanis: 2027 need structural changes: level of EDF and level of our members. Very different levels of development of DPO's in member states. National counsels that our not funded at all, not consulted,...disparities tussen NGO's. EDF disability research institute. History will be written by a human rights historian.

### **EDF strategic framework 2017-2021**

Catherine ppt

Ethical policy on financement will be included!

Overcome language barriers. New ways and technologies to make sure all people can participate. Provide adequate support and training os people can use the new technologies (in response of question from Gisèle)

Gisèle: éthique c'est important. Nouveau Loi sur les asbl obligations de transparence. Les donations anonymes sont interdit. Ns soyons pas naïve. Réalité que peuvent être très implaisant sur l'éthique. L'Europe n'est pas assez visible, assez proche,... ns devons mettre en place in réflexion comment pouvons no rentre notre travail accessible au pmh qui sont active sur le terrain. Je parle pas seulement du question de 'langue'.

Yanis : evolving doc. I propose that the secretary revises the doc based on what is said today and tomorrow and threw written consultation we approve it.

### **Madrid declaration**

Text should be reviewed and revised based on what has been said today and tomorrow, should be ready in a week (same procedure as for strategic framework).

### **Doc women forced sterilization**

Ana

Context: introduction, definition.

Info about relationship between legal capacity and forced sterilization. Link it with EU and member states. Istanbul convention art 39 def. and consideration of important fact.

Collect testimonies.

Prepare publication.

Every y 100 pmh are sterilized in Spain. Numbers are growing little by little.

Approved.



## Round table

Gunta Anca – EDF vice president

Nujeen Mustafa– Syrian Refugee with disability

Laura Albu – European Women's Lobby: more similarities you would think. EWL biggest women's movement since 1990's. EDF is one of our European networks. You have the same questions on diversity and inclusion. We have our declaration, but why doesn't it work. As NGO movement we should learn more on techniques to negotiate with them (MEP's), use their techniques but not their ethics. Why don't we have funds? Work more together! Training en teaching on what are we doing on European level and national level in our own groups.

Maciej Kucharczyk – policy director at age platform Europe. EDF president yesterday said our movement should be more inclusive! We got more to together. Across different movements but also in society. Pillar of social rights: does not cover all topics we work on, but at the same time it is one of the main things we can expect in this time, huge opportunity even if this is limited. Not proposal that has come out of the commission. Industry is not very favorable for this proposal. between different stakeholders, social partners. Hopefully it will be proclaimed in 17 November in Sweden. Many members are not aware of the existence of CRPD or don't see how they can use it. How to make old age disability more visible. Have been very active on European projects, use this opportunity to work together Age and EDF, NOOZO.

Allan Pall – Secretary General at Youth Forum. A lot of barriers to participate at European level organizations. Struggling for resources, accessible accommodation, web tools,...  
ex. Young LGBT disabled person. Society is preconditioning us to be boxed in small groups.

Equal treatment is of the agenda. How do we look at intergenerality. Different groups. Social pillar: last 10y very little discussion on social Europe. Opportunity, if we work together, we can amplify our voices, stronger.

Enrique Guerrero Salom – European Parliament Committee on Development

Importance of lobby's! they do have an influence to introduce disability on every discussion the European parliament makes. Social dimension has largely be ignored in Europe. Probably why there is a disconnect of the people with Europe . pillar is a fundamental tool. Internal cohesion, solidarity has been missing the last years. Role of European Parliament can be very important for their proposals and strategies.

Klaus Lachwitz – secretary of International Disability Alliance

2004 UN invited diplomats and global DPO's to come to New York, to discuss CRPD. 300/500 where pmh. 14days of discussing the articles of the CRPD. Main contents, main ideas,... were already in that draft. Global DPOs: world federation of the deaf, inclusion international, disabled people international,... We should not separate now, should set up a network. International union has been set up. Need a secretary, try to influence the implementation CRPD at international level. 2 offices New York & Geneva (each location staff of about 4 people). Valdimir Cook director from Serbia, human

rights expert. You must do more for the global south. Industrialized countries were trying to influence everything (had the money to do so). Now: African disability forum, arab org of pmh, Asian disability forum, Riadis (org of DPO's in latin America), pacific diss forum and EDF. Beginning not a legal entity, administrative was done by EDF. 2013 alliance has a legal entity, new year in 2 years ( we can pay the staff, can have a bank account,...)

There are many alternative reports send to the committee. Made by local DPO's, IDA can try to give them support. Combine grassroots knowledge and human rights knowledge. 2000-2015 millennium goals, term disability was neglected! Today 17 SDG: several references. Ex. 4 to 2030 inclusive education (on basis of art 24 CRPS, we are fighting for this). Ex. 2030 'inclusive' work. Term disability in some of SDG's (IDA did fight for this.)

#### Questions & answers

- Need people with disabilities in youth group! A way to change things. teaching young people, empowerment.
- Single issue approach, fragmentation.
- Womens lobby: 2 kinds of organization: national coordination level & European network organization who have to be representative of at least 10 countries, EDF is one of them. Using FEMtalks (like TEDtalks) on woman with disabilities, prepare toolkits to be used on national level
- IDA: new member dementia international, elderly become involved. Conflicting with art 12 and 19. They want to be under the roof of CRPD, challenge for all of us.

Emergency resolution: accepted

Marrakesh treaty: accepted

Madrid declaration: follow up.