Participation of persons with disabilities in policy and decision-making

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Overview

- Participation as a general principle
- Representation: NGO and DPO
- Civil society participation in a developing country: Zambia
- Tokenism vs. meaningful involvement
- The European Disability movement and its current involvement in policy-making
- Conclusion & Discussion
I. Participation as a general principle

- Concept of participation in international law: breaking down barriers that prevented persons with disabilities to participate in the community at all levels

- Council of Europe Action Plan 2006-2015:
  ‘The key objective of the Disability Action Plan is to serve as a practical tool to develop and implement **viable strategies to bring about full participation of people with disabilities in society** and ultimately mainstreaming disability throughout all the policy areas…’

- Participation is a leitmotiv in international documents (CoE REC(2006)5, CRPD)

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- Essential prerequisite to achieve social inclusion
‘Nothing about us without us!’

This is a longstanding motto used by the disability movement

What does this mean? Literal interpretation?

No decisions affecting the life of persons with disabilities should be made without persons with disabilities

Persons with disabilities are experts by ‘lived experience’ – does not mean they are experts in all fields

Challenge: how far we can take this principle in policy-making?
Participation of groups facing multiple discrimination

- Disability is a cross-cutting issue – there are persons with disabilities who are facing specific barriers and experience multiple discrimination

- Generally lower levels of participation in society than other persons with disabilities
  - Children and young people with disabilities
  - Girls and women with disabilities
  - Ageing people with disabilities
  - LGBTQ people with disabilities
  - Persons with disabilities from migrant communities
  - Persons with disabilities from minority communities
II. Representation: NGO and DPO

- Who should represent the group?

- **NGO**: organisation for persons with disabilities (family organisation, human rights NGO, etc.)

- **DPO**: special form of NGO; organisation of persons with disabilities (lead and operated by persons with disabilities)

- Thematic organisations (employment, education, accessibility etc.)

- Organisations representing certain parts of the movement (persons with visual impairment, persons with psychosocial disabilities etc.)
Representation: Who is the ‘us’?

- The disability movement is not homogenous – different groups, different aims: often fragmented
- E.g.: inclusive education – deaf community
- Some parts of the disability movement are often left out from negotiations:
  - organisations of persons with intellectual disabilities
  - organisations of persons with psychosocial disabilities
- Who is actually represented? Who is not represented?
III. Civil society participation in a developing country: Zambia

- UN CRPD ratification: 1/2/2010 – state obligation to ensure the participation of persons with disabilities in policy and decision-making. Monitor the Convention with the involvement of civil society.

- Focal point: Ministry of Community Development appointing focal point persons in relevant ministries.

- Article 33.2 framework: **Independent Monitoring Unit** (IMU) – initiated by civil society, not CRPD compliant (lack of collaboration with the NHRI).
Zambia

**Strengths:**

- Civil society is actively engaged in the implementation and monitoring process of the CRPD
- DPOs are aware of the obligations under CRPD and of important national issues (e.g. legislative changes)
- Using CRPD as an advocacy tool
- Planning advocacy in a strategic manner
- Pro-activity
- Awareness-raising in the community

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Zambia

Challenges:

- Developing country – no internal funding for the implementation of the CRPD
- Government did not even provide funding for the established IMU
- Funding from international donors came to the end in January 2013 – sustainability?
- IMU is lacking the independent element – better working relations need to be established with the Human Rights Commission

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IV. Tokenism vs. meaningful involvement

- **Tokenism**: formal consultation, no impact

- A typical case of tokenistic participation:
  
  A few randomly chosen organizations are invited to give their opinion on a draft written by public officers - too late to make any substantial changes, lack of broad public consultation with all the relevant stakeholders, no impact to be made by DPOs

- **Meaningful involvement**: make real impact, active presence during negotiations

- New, collaborative, accessible and transparent working methods need to be established

- Prerequisite: Empowerment and capacity-building
Criteria of effective participation in policy and decision-making

- Participation from the very first stage
- Accessibility
- Broad collaboration
- Continuous evaluation
- Transparency
- Stable funding for operation provided by the government or private donors
Challenges in effective participation

- Sustainability is very challenging (What’s when the money is gone?)
- What satisfies DPOs (‘experts by lived experience’) is not always compliant with international law
- Range of critical success facts seems broader than financial issues
- Establishment of collaborative working relation with public administration, National Human Rights Institutions
- Measuring real impact
- Centralisation vs. Representation
Social inclusion: common interest

- Visibility of persons with disabilities – less stereotype
- More sensitive and tolerant society
- Valuing diversity – inclusive education is not only good for persons with disabilities, but to anybody
- Participation in the society – presence at the labour market – income – becoming taxpayer – less dependency on the social welfare – decrease poverty
- Persons with disabilities can make important contribution to the society
- Barrier free society would be beneficial for a broad range of people regardless of disability
V. The European Disability movement and its current involvement in policy-making

- **European Disability Forum (EDF)**
  - Based in Brussels, Belgium
  - Was created in 1996 by its member organisations
  - Independent DPO that represents the interests of 80 million citizens with disabilities at EU level
  - Lead by persons with disabilities
  - Umbrella structure – member organizations are the national umbrella DPOs
Nine priority areas for EDF

■ Actions towards the **full employment of people with disabilities**

■ Obtaining a comprehensive EU law that will **combat discrimination** against disabled people in all fields of life;

■ Promoting the recognition of **human rights** of people with disabilities;

■ Promoting and achieving **access for all**, particularly in the field of transport, built environment, information and communication technologies;

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Priority areas for EDF...

- Promoting full participation in society by access user-led, quality and affordable personal and social services

- Playing an active role in the debate on the future of Europe

- Mainstreaming disability in development cooperation and EU pre-accession process

- Building up a stronger and unified European disability movement

- Ensuring the diversity and the disability of all impairment groups in EDF work and priorities

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V. Conclusion

- Participation is an extremely important principle to achieve social inclusion of persons with disabilities
- Breaking down barriers that prevented persons with disabilities to participate in the community at all levels
- Involvement at all levels of policy and decision-making
- Capacity building, accessibility for the organisations of persons with disabilities
- Participation is mainly not a money issue – other dominant factors
- Ensuring meaningful involvement instead of maintaining traditional tokenistic participation
Discussion

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Thank you for your attention!

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