**Supporting the independent living of persons with disabilities – Role of the European policies and institutions**

**European Parliament – 26/09/2017**

**Opening**

MEP Marek Plura began proceedings by welcoming participants to the meeting.

**Introduction**

**Jamie Bolling, ENIL Executive Director**

Jamie Bolling gave the introduction to the meeting. She pointed out that it has been shown that disabled people disproportionately affected by cuts. In Sweden her own allowance was cut by 50%. She was lucky enough to find work to be able to get by, but wouldn’t have been able to find work if it hadn’t been for the experience from her volunteer work. One girl of 19 in Sweden was placed in an institution for elderly people. ENIL had to fight to get her out. Even in Scandinavia this is happening.

According to UNCRPD this shouldn’t be happening. There shouldn’t be cuts but increases. We need help to make implementation happen at the national level.

**Eleanor Lindsay, Disabled People Against Cuts – DPAC (United Kingdom)**

When countries sign up to the UNCRPD, they can also sign up to optional protocols. Many do not, but in the UK the Labour government at the time signed up to them. In 2012 Debbie Jollie and Linda Burnett looked up the option of using optional protocol 6 for first time. Before then it had not been used by any country. DPAC’s call was unprecedented. They saw that there were violations in the UK.

They released a report of over 30 violations since 2010, when the Conservative party came to power. They met with the Secretary to the UNCRPD committee in London to put forward the case of grave and systematic violations of rights. The UN then agreed to carry out an unprecedented enquiry. In October 2015 a team of rapporteurs came to UK to visit devolved nations. They interviewed over 200 people and produced 3000 pages of evaluation. Observations were made particularly on Articles 19, 27, 28. The UK was found guilty of grave and systematic violations of disabled people’s rights.

The UN can’t force the UK to accept its observations, but nevertheless it is very rewarding to see recognition of the situation. Now the truth has been shown through the UN that the UK government has to be responsible for disabled people’s human rights in UK, and an authoritative body says so.

Eleven recommended actions were given for the government to take into account. All of which were ignored. The government rejects the findings and continues to say spending on disability benefits is £50 billion a year, making them most generous of governments. This is shown to be a lie. Spending on working age disability benefits comes to £28 billion.

Spending on the Disability Living Allowance and Personal Assistance has gone down. It amounts to only 0.8% of national income, most of which was spent in the late 90s. The government has slashed the budget by £6.3 billion since 2010.

In the UK the right to independent living is under threat due to under-funding. It’s another right likely to be threatened by Brexit as so many assistants come from EU countries.

A normal periodic review by the UN was undertaken recently, with a wider scope. The findings of this review are equally as damning. The acts of the British government were seen as a “human catastrophe” and the Committee has said that UK can no longer call itself world leader for disability rights.

The Government has also been told that it cannot pass the blame of the crisis in social care onto local authorities, and make them responsible for getting funding. The government has been found guilty of worsening on every article in UNCRPD. All this can be viewed on the UNCRPD Committee website. From now on there will be an annual review of the UK government.

**Bengt Westerberg, Former Minister for Social Affairs and Deputy Prime Minister of Sweden**

We can confidently say that beneficiaries of Sweden’s independent living fund can say this has been a success.

There has been a growth from 7k in 1995 when it was introduced, to 16k beneficiaries, which is 0.16% of the population of Sweden. The hours of assistance have also gone up.

However, personal assistance in Sweden is eroding now. This is especially the case for fundamental needs, and the interpretation of what constitutes a fundamental need has become more restrictive. Fewer people are now considered to have fundamental needs (more than 20h assistance per week) and so many have lost their assistance. Most politicians accept this and do not take any counteractive measures.

The cost of providing assistance increases 3% a year, but the compensation given form the government has increased less than half of that amount. This will undermine the quality of services. One reason is because the government considers costs to be unsustainable. The running cost have increased from 1.4 billion kronor in 1995 to 3 billion Kronor.

The UNCRPD recognised the right to adequate living and improvement. If you need personal assistance, you might need more hours of support to improve your standard of living. What’s more, 1.4 billion kronor back in 1995 then corresponds to 3bn kronor nowadays in cost terms, so it is normal that there is this rise. People with disabilities shouldn’t have a slower increase in their standard of living than others.

The Swedish government says that requests for assistance are too high, and blames municipalities for this increase.

Personal assistance is a modern form of support, giving disabled people the chances to live as others do. More people should get the chance to this, not fewer.

**Testimonies**

**Kapka Panayotova, Centre for Independent Living Sofia (Bulgaria)**

Kapka Panayotova explained that she was at the meeting to talk about the effect of austerity on disabled people in Bulgaria. However, in Bulgaria, she pointed out, they have not been affected so much by the last financial crisis, because the disability allowances are so low that they leave no room for cuts. 60€ a month is what people get for a disability pension. 20€ a month is for integration allowance. There has been permanent austerity for decades.

Kapka became disabled at the age of 7 months because of polio. Luckily her family gave her love and a good education. Now she has a job, even though she has a status of 70% inability to work. In reality she works 10 hour days, including weekends sometimes. She lives alone, pays bills and pays a personal assistant. Many disabled people are not as lucky. Hundreds are abandoned and placed in care. These people are deprived of education and enjoyment of life. Institutional care workers treat them as stock.

De-institutionalisation in Bulgaria never really happened. Millions of euros have been spent on small group homes, but these homes give the same kind of services. The people’s daily activities are controlled.

She showed participants a picture of a young girl called Vetislava. She has a physical disability. She can make her own decisions about life. However she is placed in an institution. Bulgaria fails to allow her to live independently. She simply sits in the garden of the institution staring into empty space. She won’t easily find a job, and if she leaves the institution she will get almost no financial support, so she is stuck in the institution forever. She needs accommodating housing, support assistance, assistive technology, etc.

**Corinne Lassoie, Ensemble Vie Autonome (Belgium)**

Belgium is complicated because of its regions. Wallonia is a bad example. It has 10 years’ experience of personal assistance with around 400 beneficiaries. The system is not looking into personal needs, offering just 16 hours a week of personal assistance. At the moment of the 6th reform of the Belgian state, it went backwards again. Now a new system has been proposed by ministers which manages insurance through the health insurance companies. Many Belgians fear going back even further towards a medical approach. A person has no rights to choose the timing of the services provided to them.

Wallonia has a big history of institutions. Figures show that 63% of the disability assistance budget goes to institutions, 5% to community services, and 0.3% for personal assistance. The problem is that Wallonia has a paternalistic vision. There is a fear of taking on personal assistants. Many persons with disabilities choose institutions because they don’t want to depend on families. People who stay at home often face difficult situations. Administrative agents coming to visit them have often seen terrible things and have themselves needed therapy for things they’ve seen. People are afraid.

**Stelios Kympouropoulos, I-Living (Greece)**

Greece has something in common with Bulgaria, the word “nothing”. Greece was never an EU Member State when it came to disabled people’s rights. The good news is that disabled people have not suffered cuts, but the bad news is that there is simply no independent living allowance to cut. There is nothing allowing disabled people to choose their way of living, despite the CRPD. Sadly, the situation was exactly the same even before the crisis.

The needs of people with disabilities are covered by families when they can offer support. Otherwise they live in one of the famous Greek institutions, where people are tied up, wear diapers, and are given medication to keep them quiet. Even for those with no intellectual impairments, they sometimes end up with them because of their living conditions.

Stelios described how a colleague in Greece explained “I don’t feel European, even though I live in Europe. If I wanted to join this meeting I would have to hire an assistant with my own money, and I prefer to save this for the time when my parents are no longer able to care for me.”

The budget spent on disability in Greece is half of what it was before the crisis. The medical model is used to assess people’s needs. The more a person is hospitalised, the more disabled they are considered to be.

**Aurélie Baranger, Director, Autism-Europe (EU)**

Autism-Europe has been a long standing member of the coalition against the cuts, because it has seen how harshly the austerity measures have affected people on the autism spectrum and their right to receive adequate support in the community.

Some people on the autism spectrum need a very high level of support. Receiving adequate support is a lifeline for many autistic people who need help to do things like washing, cooking or going out into their community. Reduction in the availability of care result in social isolation and further discrimination.

Autistic people are more prone to be forgotten, because they have a hidden disability (it is also the case for people with psychosocial and intellectual disabilities, for example). Disability assessment are much more difficult for them. Actually we know that many adults on the autism spectrum remain undiagnosed, despite experiencing great difficulties in their daily life, for example struggling to find and maintain a job.

Disability assessments that rely heavily on what the applicant tells you rather than a physical examination, in other words that is more subjective, is less likely to score highly or at all. It explains that autistic people often face greater difficulties, when assessments are reviewed.

MS Baranger shared a testimony from Catherine, a woman in the UK with a learning disability, recently diagnosed on the autism spectrum, Catherine explains:

“A lot of people in the U.K. have had their disability benefits stopped and have to challenge it. The U.K. government has decided that anyone who gets disability living allowance now has to be retested and you have to get 8 points to qualify for it. A lot of people with hidden disabilities like autism are not getting the new payment and have to fight for it which leaves them struggling for money to help them with their disabilities. I have just been awarded mine after fighting for it as the first time the government turned me down. I have to reapply for it again in 10 years’ time. The assessment and the form is a worry for people with disabilities as a lot of people have had to take the government to the appeal court to overturn the decision made for the benefits.  The government is not really thinking about people with disabilities and it makes them angry”.

Catherine, being a self-advocate who works in a disability organisation, is well equipped to challenge the decision, however it is likely that many people with hidden disabilities are struggling at the moment due to similar decisions.

**Interventions from members of the European Parliament**

**MEP Helga Stevens (Belgium)**

MEP Helga Stevens pointed out that unfortunately there is little that the EU can do about budgets for personal allowance, but that she will include what she hears today in her report on the UNCRPD implementation by the EU. They’re now in the stage of looking for amendments and will soon be able to hand the report in to the EP, asking for more personal living fund as this is in the UNCRPD. It is hard to convince people when they do not know what it is like to live with a disability.

In the European Parliament a text on the Accessibility Act was recently passed. It was rather weak but it is better than having nothing. People wanted to water it down, but they don’t understand the importance of including disabled people.

The USA is more advanced than we are in the EU. They show us we can be better. It is a very capitalist country, yet ahead of us on this. It is a paradox.

The UNCRPD is good but it needs implementation to follow up.

**MEP Marek Plura (Poland)**

MEP Marek Plura stated that he agreed with MEP Helga Stevens. The EU is not one country with one solution. Each country is setting its own solution, yet we have common problems. This is why we take up common initiatives such as the Youth Guarantee Programme. It’s one big programme to answer problem of youth unemployment.

The lack of possibility for independent living is a common problem. Disability touches us all in different stages of life. MEP Plura hopes we will soon implement a new perspective for an EU without barriers 2020-2030. He hopes there will be a solution to our problem and that it will be transferred from a problem into a goal. He would like to see an EU 2030 where independent living is a sign of stability. But this should not just come from EU programmes and money, but also a task for local governments and us.

It is important that our activities make an impact with our political activities. We need to speak a common language to be heard by the Commission. This conversation has been taking place in the EP for a long time. A difference can already be seen. Commission now aware that money should not be being spent on institutions. When people live independently they can pay taxes and profit from society. I’m convinced that investment in independent living will pay off thanks to our investments.

**MEP Mairead McGuinness (Ireland)**

This issue was first brought to the attention of MEP McGuinness when she began at the European Parliament in 2005, of EU money being spent on institutions. Her office worked on this. It took a very long time but progress has been made. Now we need to monitor how these changes are being implemented.

The question is how to make things better, quicker. In Ireland there is an autism advocate who ran the “As I Am” online campaign, raising lots of awareness. It is simply about getting people to understand these people are part of our societies. It is important to keep your voices heard at every level.

The Prime Minister of Ireland said he would ratify CRPD but we need to pressure him to do so. We need to work with politicians constantly. Eventually changes come, even if slowly.

**Luk Zanderloo, Secretary General of the EASPD (EU)**

Luk Zanderloo outlined several key messages to take away from the event:

1. The people present at the meeting are in the EP, which is there to hear the voice of the people, and they are stating, “No pity. Rights!”
2. People with disabilities are disproportionally affected by austerity. The crisis could have been an excuse to get rid of an outdated system, but this didn’t happen. The crisis was used to cut more innovative processes. It is not just about taking away benefits. It’s about taking away the right to enjoy society.
3. Change is needed. The mentality must change from cost to investment. From a patronising to an empowering model. Work must be done in co-production, with persons with disabilities at the steering wheel. We must reroute money, because there is money in the system. It must be spent on more independent living schemes. And in countries where there is no allowance, the EU should intervene with structural funds.
4. It is hard at the EU level to help, but they can offer financial projects to facilitate independent living, shifting and rerouting money. There is also a soft law approach, like exploring how the Horizon 2020 money can support innovation here.