EUROPEAN ALLIANCE AGAINST DISABILITY CUTS: Meeting Report

Introduction

On the 2nd December, right before the International Day of persons with disabilities, the EU Alliance against disability cuts held an open meeting in the European Parliament hosted by MEP Richard Howitt (S&D, UK). The event provided an opportunity to take stock of the deleterious conditions in which many disabled persons find themselves after substantial cuts were applied by national governments to their allowances and support services.

Undoubtedly the economic crisis in Europe has affected all European citizens, however, the most severely and disproportionately hit have been and unfortunately still are people with disabilities. These cuts primarily affect services aimed at promoting and facilitating Independent living, such as personal assistance, other community-based services and direct payments which in turn have negative consequences on the enjoyment of human rights.

The EU Alliance Against Disability Cuts works together to expose this Europe-wide social and human rights crisis, by raising awareness about it and putting it higher on the European political agenda. During the event, a proposal for a Resolution of the European Parliament on the effect of cuts in public spending on disabled persons in the EU was presented.

The EU Alliance against Disability Cuts is initiated by the <u>European Network on Independent Living</u> (ENIL), with the support of the <u>European Foundation Centre</u>, the <u>European Disability Forum</u>, <u>Inclusion</u> <u>Europe</u>, <u>Mental Health Europe</u>, <u>Autism Europe</u>, the <u>European Network of Users and Survivors of</u> <u>Psychiatry</u>, Disabled People Against Cuts and the <u>European Association of Service providers for</u> <u>Persons with Disabilities</u>.

Welcome by Richard Howitt

British MEP Richard Howitt (S&D) welcomed participants to the meeting, reminding everyone that the event coincided with a landmark day. It was on this same day, the 2nd of December 2015, that the Accessibility Act was finally adopted after a five-year campaign. In truth, he admitted, the Act offers a flawed proposal, but stressed that it was at least significant that it is now out there and could be negotiated on. He reminded those present that it is important to make the connection, and continue reminding people that the continent and society in which we live should be more accessible. It is not just in the public sphere that we see the effect of cuts. Even in people's own homes the withdrawal of support and assistance is making life worse. The question that needs to be asked is therefore the following: what is the point of making society better and more accessible elsewhere if people can't live well in their homes?

MEP Howitt pointed out that he applauds the quest of ENIL. Before they began working around this issue, the notion of the importance of independent living remained absent from meetings on disability. ENIL is largely to thank for pushing it onto the agenda, and for headed the fight against cuts. The organisations represented in this meeting, he underlined, showed the widespread anger at cuts taking place across Europe.

The problem is one that affects all of Europe, but MEP Howitt presented the example on the troubling situation in his own country, the UK. The British government has decided that cuts fall in two areas: local government and welfare. In both areas, people with disabilities are the ones who suffer most. Regarding local government this stems from cuts to services and assistance. As for welfare, whereas

the average person receiving benefits will lose out on £567. For a person with disabilities, the amount lost in welfare rises to around £4,410. The UK has also shut down it Independent Living Fund. In the UK we have seen people who have had essential welfare benefits cut and died as a consequence. Furthermore, 80 people a month being declared fit for work and dying as a result.

MEP Howitt reminded us that whilst we talk about dignity and relieving people from poverty, this issue is about living full stop, and not just quality of life. We are seeing alarming situations throughout Europe. In the Netherlands and Ireland, for example, cuts are also very severe, and France is still placing dependant people in other EU Member States to get treatment, as it proves less expensive to subsidise this than to provide the treatment at home. This approach doesn't take the person's need to be near their family, friends and familiar surroundings into consideration at all. In Hungary 3,000 disabled workers have had their work-support subsidies cancelled, and in Greece 10,000 people poured onto the streets of Athens recently to protest about cuts. People are angry and ready to do something about it.

Other people are affected by these cuts too, such as assistants and care workers whose services can no longer be afforded by the people who need them. The result is more poverty, social exclusion and further institutionalisation. Of course, MEP Howitt reminded those present that difficult choices have to be made when it comes to national budgets. These are difficult choices, but they are indeed CHOICES which, he pointed out, makes it all the less defendable that people with disabilities are targeted so severely in these cuts. This group is one of the most vulnerable. In any other context we would call this bullying. What this movement demands is that disabled people be safeguarded against further cuts.

Even the UN Committee on the Rights of Persons with Disabilities (UNCRPD) itself, in its feedback on the results of the EU's Strategy on Disability (2010-2020), expressed concern about austerity, saying:

"The Committee is concerned about the number of boys and girls with disabilities living in institutions across the European Union who have no access to mainstream inclusive quality education. It furthermore notes with concern the adverse effect austerity measures have on availability of support services in local communities for families with children with disabilities, that disability strategies do

not include children, and that the European Union Agenda for the Rights of the Child has expired."

"The Committee is concerned that austerity measures have resulted in cuts in social services and support to families and community-based services, among others, which restrict the right of persons with disabilities to family life and the right of children with disabilities to live in family settings."



"The Committee notes with deep concern the disproportionately adverse and retrogressive effect the austerity measures in the EU have on the adequate standard of living of persons with disabilities."

MEP Howitt pointed out that this meeting will ask the question of what we will do about the worrying situation, stressing that the politicians need to know the problems and the fact that policies are inconsistent with our obligations under the UN Conventions, against human rights. The aim of this meeting of the EU Alliance Against Disability Cuts is therefore to call on all Member States to stop cuts

to community-based services and personal care for persons with disabilities and, where these do not exist, to establish them in any case. The call must be heard, and acted upon.

Peter Lambreghts - ENIL

ENIL has been fighting for decades for persons with disabilities to be able to enjoy the same rights as other people. It has, he pointed out, been a long, hard struggle. Many of the role models of those involved in ENIL were faced with a time when the entire focus around the subject of disability was on a purely medical model. People with disabilities were seen as pitiful objects, and were put in institutions far from society. Luckily the rhetoric had changed and in many places the reality is moving in the right direction. There is certainly still too little in the way of equality, but we have achieved a lot in only a few decades. The UNCRPD gives us guidance on how these rights should be realised and implemented. Article 19 of the Convention, on living independently in the society, is particularly important and talks about deinstitutionalisation. Mr Lambreghts explained the feeling of positivity in 2006 when UN convention became reality and started being ratified so quickly throughout world. The atmosphere was good and it seemed the job was almost done. The positive feeling didn't last very long however. In 2008 the financial crisis emerged and instead of the Convention bringing about real changes we saw the gap begin to grow again. We see that we are losing things we spent so long fighting for.

Mr Lambreghts explained that ENIL was not alone in its concern, and joined forces with European Foundation Centre, the European Disability Forum, Inclusion Europe, Mental Health Europe, Autism Europe, the European Network of Users and Survivors of Psychiatry, Disabled People Against Cuts and the European Association of Service providers for Persons with Disabilities. Under ENIL's initiative, the European Alliance against Disability Cuts was born. The fact that people with disabilities are hit harder than others was previously not even known on political level. People were increasingly being pushed into dependence and put in trouble. Their organisations didn't have the power to react quickly. Through the Alliance, ENIL and its partners sought to bring this issue to people's attention. The fight against cuts became not only a national battle, but also a European one.

Finally, Mr Lambreghts underlined that one of the Alliance's objectives going forward is to have a resolution on the effect of the crisis, asking Member States to stop with these cuts, and indeed to reverse them.

Laura Jones – Secretary General for the European Platform for Rehabilitation

The <u>European Platform for Rehabilitation</u> (EPR) is a network of 29 organisations in 17 countries providing services to people with disabilities. It was one of the research partners in the call for tender launched by the European Foundation Centre. Its vision is that its members and service providers contribute to a society where every person with a disability and other people in vulnerable situations have access to the highest quality services, creating equal opportunities for all and independent participation in society. They give great importance to promoting community-based services, and underlining that these services should allow access for all. EPR wants to help strengthen the capacity of users, and which it does to a certain extent by engaging in policies relating to social services.

Ms Jones would present some of the key findings and an overview of the research. European Foundation centre launched call, and created a consortium of foundations on human rights and disability, specifically looking at the implementation of the CRPD. The resulting project aimed to see to what extent measures provoked by the crisis impacted on the lives of people with disabilities as well as the implementation of the CRPD. The study took place in 2012, but now would be a great time to relaunch a new study. It has been seen, however, that the trends have not been reversed.

There was a desk study produced of the 27 Members States in the EU in 2012, reviewing existing European statistics, and then a more in-depth study on the cases of Greece, Hungary, Ireland, Spain, Portugal, Ireland UK, talking with specialists, service users and local authorities. It takes UNCRPD as reference points regarding rights. One challenge was that of statistics. It was difficult to find sufficient information to make proper comparisons between different Member States. In some countries there are gaps in the data, especially in countries where it was optional to compile statistics. The study looked at social services, social security, benefits, and allowances for disability costs.

The main impacts on social services that were found were direct budget cuts, delays in funding, closure of services, as well as staff and salary cuts. In seven EU countries there was shown to be a reduction in the number of staff. In four countries there were common cuts in salaries to staff. It was also observed that there was more standardised care taking place, with the danger being that this does not necessarily meet the needs of individuals.

Some examples of specific problems found were:

- Inclusive education in Portugal without ensuring there is support for children with disabilities once they are in the mainstream system
- Cuts to benefits: in Ireland this was between 5-8%
- Delayed payments: in Spain this was 9-16 months
- Increase in user charge for nursing care: in Estonia this was 15%
- Increased cost of medicine
- Stricter eligibility criteria: Sweden, Spain and Hungary
- Hardening of public opinion. Portrayal of people with disabilities in the media. Promoting stereotypes of scroungers etc.

A broad range of rights have been affected. It has an impact on the CRPD's Articles 19, 20, 24, 25, 26, 27 and 28 or the CRPD.

The study also unveiled a sharp rise in unemployment and poverty. The differences between people with disabilities and those without disabilities has not changed since then. There is around 20% more unemployment among persons with disabilities, and they are roughly 8.5% more likely to find themselves living in poverty.

In terms of studies carried out by EPR alone, in 2014 they conducted a study on transition services and mainstreaming (namely for young people transitioning from education into the labour market). They wanted to analyse good practice, but also saw unfortunate trends caused by cuts to services limiting their ability to act. There is still increasing demand for such services, but this was also shown to be because the services are new and people are just finding out about them. There was also shown to be pressure to make things as cheap as possible. Often the cost of services is being judged and not so much the quality.

However, Ms Jones concluded that progress is happening. Vocational rehabilitation is progressing, acting as a key way of helping persons with disabilities access the labour market. Estonia is embarking

on work ability reform, the Netherlands is developing a participation pact, inclusive education is gaining momentum in Flanders and the Czech Republic, and we are seeing a movement towards deinstitutionalisation taking place in Finland.

EPR thinks that concept of social investment is one of the key tools to promote expenditure in the social sector, as it not only reduces costs for more intensive care further down the line, but also allows people to take part in life and contribute to their community.

Hans Dubois – Eurofound

Mr Dubois presented some work produced by <u>Eurofound</u> on access to healthcare for people with disabilities. On average people with disabilities have more healthcare needs so this is something that is quite relevant.

Their research has looked at different types of access and which people are at risk. This has been done in the context of the crisis. The first set of data looked at unmet medical needs, the main reason for which was shown to be its expense. The cuts themselves really began to show themselves a little while after the crisis began, namely in 2010 and 2012.

Even in relatively well-performing countries. When it came to delays to receiving treatment countries such as UK, Spain and Sweden scored quite badly. At the time of the survey, which was 2012, 21% percent of people in the EU classed themselves as having a disability, which was set under the criteria of having activity limitations. Compared to people without disabilities, persons with disabilities consistently faced greater problems in terms of waiting times, costs and distance to receive treatment. This seems to be in direct conflict with article 25 of the UN convention. Many of the problems faced by people with disabilities are the same as people without disabilities, only more intense. There were also shown to be long-standing problems that existed before the crisis, but intensified owing to cuts.

During crisis less funds have been available for addressing access problems, including access to healthcare, and physical access to buildings and vehicles. For intellectual disabilities, cuts have damaged access to information. Staff have also been shown to have less time to deal with people and there is increasing reliance on untrained professionals. Member States have sometimes tried to maintain access, with co-payments being maintained, but maintained rights in legal terms are unfortunately not always reflected in practice. Many people remain unaware of their rights, some don't seek help because of stigmas, and some don't do so because of mental health problems.

Sometimes people are using emergency care as a way to access healthcare, waiting for the problem to become serious before seeing someone, and sometimes not getting the type of care that is appropriate. Community care has been seen as a way of improving the situation, although even this has sometimes been cut (as was the case in Ireland) because the contracts carers were on made them easier to get rid of.

Catherine Naughton – European Disability Forum

Catherine Naughton, Director of the European Disability Forum, began by highlighting that despite the evidence of structural changes affecting endangering the rights of people with disabilities, the UN's concern of austerity's role in bringing about human rights violations as a human rights abuse, and despite all the political talk, individuals are still experience misery. As we have seen in this meeting, certain measures such as leniency from services are emerging, but this is not really what people with

disabilities and their families are asking for. What they want, Ms Naughton pointed out, is simply to have access to same services as other people.

The <u>World report on disability (2011)</u> focuses on costs in all services, not just health. It looks at costs incurred for persons with disabilities in terms of, for example, transport, housing and support for children in school. Even before austerity measures really starting to kick in the way they currently are, people with disabilities were already starting off on the back foot do to the extra costs incurred in these areas. As mentioned before, the UNCRPD recently told the EU that the welfare cuts affecting people with disabilities is an abuse and asked them to take responsibility to ensure people are protected from this, especially regarding the following issues:

- Children with disabilities
- Right to family life
- Right to standard of living

Ms Naughton warned that younger generations are now again being threatened by a return of institutionalisation. It is also worth noting, she pointed out, that the UN Committee recommended renewing the Agenda on the Right of the Child.

The danger at the moment is that not only are new measures not being introduced, but former measures not being renewed either. In such a context, the important leadership we expect from EU is not happening. As such, a lot of work needs to be done during the Europe 2020 processes to ensure that these recommendations taken on board.

The UN Committee's recommendations referring to the Convention's article 28 on "Adequate standard of living and social protection" is particularly relevant. Here, the Committee said the following:

"The Committee notes with deep concern the disproportionately adverse and retrogressive effect the austerity measures in the EU have on the adequate standard of living of persons with disabilities".

"The Committee recommends that the European Union take urgent measures, in cooperation with its Member States and representative organisations of persons with disabilities, to prevent further adverse and retrogressive effect of austerity measures on the adequate standard of living of persons with disabilities, including by the provision of a minimum social protection floor".

These recommendations need to be seriously considered at the EU level.

Anastasia Tovi - Greece

Anastasia Tovi comes from the city of Thessaloniki in Greece, and is Vice-President of the Pan-Hellenic Federation of social enterprises of limited liability. Ms Tovi belongs to group A, a group that includes people with psychological difficulties. Me Tovi has been hospitalised in the psychiatric hospital in Thessaloniki. She works for a social enterprise in the city, and is in charge of a sewing workshop. Her team there consists of six employees.



Ms Tovi explains how employment gives her the ability to fight the psychiatric condition, have a better life, and earn money to achieve more independent living, the way she used to before the financial crisis. She explains it as a type of working therapy. Before 2010, she explained, her life was much better. Financially speaking, she described herself as a middle-class citizen, with

decent retirement benefits. Since the crisis she has had to show courage she never would have imagined possible, in order to cope with reductions to her pension, increase in taxes and costs of general goods, dramatic reductions in healthcare provision, as well as a lack of medical staff, medication, psychiatric units and personal patient structures such as protected apartments and hospitals.

While Ms Tovi strongly agrees with EU directive for closure of psychiatric hospitals, she asks how we can expect Greece to be ready to assimilate outside hospitals, with mental health patients. This is all the more difficult as there is a stigma, and a notion within communities that people with psychological difficulties are dangerous.

Ms Tovi concluded by wishing a steady return in Greece to the situation before the crisis, and invited participants to visit the social enterprise where she works in Thessaloniki.

Kostadinka Kuneva MEP

MEP Kuneva began by congratulating ENIL and the European Alliance against Disability Cuts for this initiative, saying it couldn't have been better timing. In Greece people with disabilities and related stakeholders have a growing fear of cuts. The fuss created is now even bigger as we are witnessing abolition of welfare benefits, which had previously been cut. Greece's latest austerity package, MEP Kuneva reminded participants, cuts amounting to 1€ billion were made to spending on social welfare. These cuts are often displayed as reforms. The results for Greeks with disabilities are social exclusion, unemployment and poverty. As for the UNCRPD, MEP Kuneva sees this Convention, which ratified by the EU in 2010, as remaining void in terms of its application.

MEP Kuneva stressed that now is needed to be the time for action, and that all relevant stakeholders and organisations need to combine efforts and strengths to prevent cuts from happening. It seems unconceivable, she said, for the EU to spend billions of euros saving banks and then to abolish its commitments to human rights. What we are left with is to continue the struggle to protect our rights of persons with disabilities.

As President of the European Parliament's Disability Intergroup, MEP Kuneva vowed to use every possible tool to form this group's vision for people with disabilities. This means equal opportunities for accessing society in its entirety, and independent living. I have been impressed that we do not actually use it as a tool, and it seems we have to repeat it again and again, so that people can finally start thinking in a different way. Finally, MEP Kuneva underlined that the disabilities people live with are not solely the responsibility of the person who has the disability, but of society as a whole. Society should therefore be held to account, and this should not fall entirely on people with disabilities.

John Evans- ENIL UK

John Evans is one of the founders of ENIL, and long-time activist. Mr Evans wanted to share some more personal reflections about the particular situation people with disabilities in the UK are currently facing. The situation of disabled people is very grave. These times are by first worst Mr Evans has experienced, stirring up a tremendous amount of anxiety, despair and fear about people's very future. Until recently the UK had one of best track records. For the most part, the country had benefited from forward thinking governments, progressive legislation, and an active and vibrant disability movement. Sadly this is rapidly changing. The UK now finds itself going backwards, facing possibility of losing the achievements that were fought so hard for. We are living through unprecedented times.

Over last five years, there has been a 25% cut to local authorities' support. In the UK, like elsewhere, disabled people are facing disproportionate cuts on services and quality of life. Persons with disability make up around 8% of the population, but are facing 25% of the cuts.

Despite protests, the Independent Living Fund (ILF) closed in June 2015, marking the end of 27-yearold fund that transformed life of people with disabilities in the UK. Since it became owned by local authorities, people with disabilities have seen gradual cuts to their care.

The Access to Work scheme is also being reviewed and having its budget cut. This scheme helped support people with disabilities in finding and maintaining employment. The UK government's latest announced public spending review does not change much from one announced in 2010, with disabled people once again at the forefront of vicious attacks hitting local authorities hard. Mr Evans reminded those present that the combined achievement in this field was being seriously attacked. People with disabilities, he reminded us, are an easy target and we must defend ourselves against these attacks.

The UN Committee will soon investigate UK on its recent actions. Mr Evans concluded on a confident note, saying that he doesn't think that all the movement has fought for will be lost because our movement is too strong.

Luk Zelderloo EASPD

Luk Zelderloo, President of the European Association of Service Providers for Persons with Disabilities (EASPD) provided a summary on some of the topics that had been mentioned during the meeting.

Mr Zelderloo pointed out that the impact of the aforementioned cuts on the health and social agenda shows itself later on. The effect, he said, is on its way. We haven't seen it yet but it is coming.

Another problem is the fact that the most vulnerable types of services are often the most innovative ones. Old institutional methods tend to survive better in times of austerity. We thus risk a process of reinstitutionalisation, and we should never accept this. Regardless of all window dressing, we have the UNCRPD, but sometimes the rhetoric of this very convention used to justify counterproductive causes. We should be therefore careful when we read implementation plans for UNCRPD in Member States, as they are not always what we want.

It has been said that "this crisis is not an economic crisis but a human rights crisis". This can be said to be very true. In many countries inclusive education schemes are being cut, for example. Mr Zelderloo pointed out that what the Alliance wants is allies in European Parliament and the Commission who would support a resolution on the effects of austerity measures on persons with disabilities. It is true

that many of the necessary measures address the Member States, but this does not mean that the European Parliament and the Commission cannot do anything.

What Mr Zelderloo suggests is needed is a comprehensive plan from the Commission, and the European Parliament can push with us for that, so that there will be a second stage of the EU disability Strategy. It is not currently on the Commission's agenda to introduce a new plan, but a new one is indeed needed.

In 2016 the Commission will look at social protection, so the Alliance should work alongside the European Parliament to look at this. During the European Semester, Commissioner Mariane Thyssen wants to use this as a tool to implement the new UN convention and the important values within it. Mr Zelderloo also suggested that country specific measures need to focus more on promoting positive change.

As for structural funds, in previous programming period funds have occasionally been used for the wrong thing. We should make sure EU Social Fund and Regional Development fund are used to promote positive changes, and employed appropriately.

The Junker package puts aside 315€ billion for risk assessment alone. It is clearly stated that this can fund areas such as social help and education (as well as the development of new social services models).

Helga Stevens MEP (ECR)

MEP Stevens began by underlining that MEPs understood the frustrations of those present, underlining that she was willing to look over all documentations and take that back to ECR and see how we can progress from there, but reminded participants that this would have to be discussed internally within the ECR before anything else could be decided. When talking about national politicians, MEP Stevens expressed her frustration with those who always tend to blame the EU for such problems, despite the fact that they are a part of the European machinery. National politicians tend to forget that it is their own governments that form the council, and furthermore that their own governments have decided on who council members would be.

Beyond this, MEP Stevens stated that she believes we have to work on two levels. We have to remember that the EU is limited in terms of both capacity, as well as competency (especially in social affairs), and that unfortunately we have to live with that fact. We can however look at how we can recommend more attention to particular problems within the Member States. MEP Stevens believes that the EU must be social, because Europe is about the citizens. It should not be the case that people with disabilities suffer more than others. This situation is unjust and shouldn't happen. Several problems caused the crisis, but the crisis has in turn created many more problems. Member States and regions need to arrange their social priorities according to their affairs. In Flanders, for example, there is a huge waiting list for medical care that has nothing to do with the crisis, but because Flanders they believe there are other priorities.

Ms Stevens concluded that in our situation we can only make recommendations, and cannot force Member States to act. The European Semester might be a good occasion to exercise this kind of persuasion.

MEP Griffin's background story is one about equality. She expressed how infuriating it is that we still have policies where people are not being treated on equal basis. It is also infuriating that we cannot take skills of people with disabilities and use them to make society a better place.

MEP Griffin also expressed her commitment to look over all the relevant paperwork, and to do whatever she could in the European Parliament and in the UK to push for disability cuts to be reversed. In UK, she said, the situation is not only immoral but also heart-breaking. The economic side of the argument is about having persons with disabilities making a full contribution, ensuring disabled people can play the full part they so rightly deserve. This idea was backed up by moderator Peter Lambreghts who stressed that, if we drive people into old-style institutional settings, in the long term it will prove very expensive for society.

Concluding remarks by Peter Lambreghts – ENIL

Although it is true that a resolution from the European Parliament does not change world, it is important to have a concrete document to refer back to when Member States try to claim their hands are tied on the subject of austerity, and point the finger to EU level. This will allow us to reply, with a strong resolution, that this is simply not true, giving us additional weapons to counter this kind of rhetoric.

The hope for 2016 will be to have a new attempt for an EP resolution, something that it is hoped can be done in close cooperation with the MEPs present, and hopefully with an attempt that will succeed in Plenary. We hope to continue making traction on the Member State level, and to continue communication with the European Commission on this topic.

With special thanks

To the European Parliament for providing the platform for this meeting. To Richard Howitt MEP for hosting this meeting and showing his continued support to the disability movement and the European Alliance against Disability Cuts, and to his office for all of their help with the logistics of this meeting. To all the MEPs who attended the meeting, including Anneliese Dodds (S&D), Theresa Griffin (S&D), Ádám Kósa (EPP), Konstadinka Kuneva (GUE), Jo Leinen (S&D), Helga Stevens (ECR), Jordi Sebastiá (Greens), Derek Vaughan (S&D), Jana Žitňanská (ECR) and Damiano Zoffoli (S&D). To Alexandru Ene from disability Unit from European Commission. To Anastasia Tovi and John Evans for travelling to Brussels to provide their valuable contributions to the meeting.