

EASPD Policy Seminar 2010

Poverty and Disability - How can we break the link?

Final Report



On the 2nd of December 2010 EASPD held its annual Policy Seminar in Brussels. The subject of this year's debate was *'Poverty and Disability – How can we brake the link?'* In order to gain a deeper understanding of disability poverty, its implications and challenges, the invited speakers were drawn from different backgrounds: poverty experts by experience, representatives of persons with disabilities, EU officials, service providers and academic professionals. The seminar further sought to address the questions of what is needed to break the vicious circle linking poverty and disability, whose responsibility it is and what role the EU has to play in the light of the outcomes of the 2010 European Year for combating poverty and social exclusion, the Lisbon Treaty and the EU 2020 Strategy.

The seminar was opened by the **President of EASPD, Franz Wolfmayr**, who remarked that it is a startling truth that Europe, one of the richest regions in the world, has 80 million people who live in poverty. Amongst the most vulnerable are **persons with disabilities who face a particular risk**. Mr. Wolfmayr mentioned that to be at risk of poverty does not only mean to have a low income and improper clothes, but also **lack of participation opportunities** in the labour market, educational systems and in civil society as a whole. Furthermore, **poverty causes stress, bad health condition and isolation**. Poverty makes you lose your personal freedom and catches you in a vicious circle. Mr. Wolfmayr referred to an Austrian study which revealed that persons with disabilities run a three times higher risk of facing poverty than persons without disabilities. He ended his foreword by welcoming a discussion on the broad topic of disability and poverty from a fundamental rights perspective.

*“Poor children are the
chronically
sick people of tomorrow”*
Franz Wolfmayr

Living in poverty - a Personal Perspective

The seminar began with a video-presentation named *“The ability to fight”*, by **Vasile Vlad**, President of **Inger NGO Moldova** and a member in the National Commission for Humanitarian Aid in Moldova. Mr. Vlad has a hereditary degenerative disease which made him dependent on a wheelchair. Moldova has ratified the **UN Convention on the Rights of Persons with Disabilities** and the attitude towards people with disabilities is reported to be positive. Thus, it is rather the financial situation than lack of political will that prevents the government from improving the situation for people with disabilities.

Consequently, the possibility for people with disabilities to be employed is limited and completely dependent on the initiatives of NGOs and civil society. Mr. Vlad stressed that social exclusion restrains the participation in normal social life and leaves people with disabilities with feelings of marginalization and powerlessness. The experience of exclusion empowered and triggered Mr. Vlad to create an NGO, which with the support from ACASA Foundation and Janivo Foundation (The Netherlands), managed to implement important projects such as a village newspaper and a computer club. Today, his NGO runs shoes and tailor workshops in his community, where persons with disabilities have an

“It is not fair that becoming a person with disability means that you must be closed in your house. A murderer is closed in jail for his crime, but we? For what?”

Vasile Vlad

opportunity to work and contribute to the society and at the same time earn some additional money, to complement the very low monthly governmental pension they receive. Mr. Vlad’s hope is that similar initiatives can be spread to all communities in the future and in that way create thousands of new job opportunities. Mr. Vlad stressed that the main motivation for his activities is to **include people with disabilities in society and make them feel useful and needed.**

Danny Trimbos and **Els Van den Bergh** continued the seminar and spoke on behalf of the Flemish organization **VZW De-Link**. Ms. Van den Bergh told that VZW De-Link was founded in 1999 and is today recognized by the Flemish Government as the organization responsible for the coordination of training and employment of **Poverty Experts by Experience** in Flanders. Poverty Experts by Experience, she explained, are persons who have lived in poverty from the childhood and who, through a 4-year training programme, have adopted attitudes, skills and the methodology necessary to apply the extended poverty experience professionally in one or more areas of the fight against poverty. The first year of the training programme is focused on research in the person’s own history in poverty and social exclusion. Also, basic training in communication, language and expression is provided. The three following years are focused on vocational training divided in several blocks. Through this part of the programme, students develop specific communication skills such as interpretation, mirroring, confronting and questioning. A structural block focuses on the structural aspects of poverty and includes social studies as well as studies in law. An integration-oriented block contains a number of subjects aimed to enable students to integrate the knowledge and skills gained through the programme. The last part of the programme is professional practice which is the first opportunity for the student to work as an “experienced expert”.

The overall objective of the training is to raise awareness about the educational- and employment possibilities for experienced experts. It further aims to stimulate citizens, services and policy makers to take responsibility for the fight against poverty. With their extended experience as their basic instrument, the experts become the bridge over the gaps between the poor and the society, i.e. **the missing link**. Ms. Van den Bergh stressed the **fundamental importance of participation** of the poor in the policy making process. Without the involvement of poor people themselves, there will always be a gap between “us” and “them”, she said.

“There are gaps in all areas of life: structural gaps, participation gaps, emotional gaps, knowledge gaps and skills gaps”

Els Van den Bergh

Mr. Trimbos, an expert by experience, described his childhood in poverty as a struggle of confused feelings of **loneliness and exclusion**. “From the eyes of a child”, Danny said, “it is very hard to understand why the society does not accept him or her”. A child that grows up in poverty does not

“I was excluded and felt sadness, frustration and anger. But I did not have the words to express these feelings. And if there is no place for feelings, the behaviour becomes inappropriate.”

Danny Trimbos

realise the impacts of this context until society put him/her in a cluster and differentiates one child from another. Mr. Trimbos further explained the missing link as the inability to express feelings and to cope with them. It is at this point where the training programme has its fundamental role to play. **Dialogue and self reflection** were explained as the essential parts of the training through which the person reaches personal growth and gains the relevant tools for inclusion in the society.

Evidence-based research: the link between disability and poverty

Herman Janssen from the Flemish organization KVG presented a recent study on “**Disability, Income and Access to Healthcare**” conducted in Flanders by a research team at Antwerp University. The quantitative part of the research compared people’s incomes with the poverty line¹. The overall results of the research show that **24.8% of the respondents live under the poverty line and 70% are unemployed**. The data was collected through surveys to service users which were disseminated among members of KVG, VFG² and beyond: institutions, day-care centers, home-care centers etc. During the qualitative part, the research team recorded, typed and analyzed discussions made with focus groups i.e. three groups of six participants of sheltered workshops. This part of the research shows that persons with disabilities who are employed are less likely to be discontent with their lives than the unemployed, due to a higher level of inclusion and participation in society. However, this group does often face difficulties in their everyday-life due to higher living costs while the salaries remain low. It was further revealed that the income from sheltered workshops is often lower than the poverty line and that the most vulnerable groups are women and young people between 18 and 30 years old. These persons cannot afford a number of necessities considered essential such as proper food, clothes and health care. Interestingly, persons with disabilities living in institutions indicated a higher level of satisfaction, which may be explained by the fact that these persons did not fill in the questionnaire themselves. But it can also be explained by the fact that they have better access to healthcare, they live in a protective environment and thus run a lower risk of facing poverty. On the debate that followed Mr. Janssen’s presentation, a question on how poverty causes disability was raised. Mr. Janssen replied that poverty worsens the effects of a disability since disabled people lack access to technical aids that facilitate every-day life and make the disabled more independent. Ms. Van den Bergh reiterated what Mr. Trimbos stated earlier, that children who grow up in poverty are more exposed to poverty due to lack of opportunities which in turn causes language, emotional, and behavioral problems. Mr. Trimbos added that it all depends on the care received. He himself mistrusted the “outside world” which led to isolation and loneliness. Finally he received therapy but stressed that choices and access to care for poor people are limited.

“Poverty worsens the effects of a disability”

Herman Janssen

¹ The relative income poverty line. i.e. when the income is 60% of the median household incomes in a country. For more information visit the website of the European Commission: <http://ec.europa.eu/social/main.jsp?catId=751&langId=en>

² Two member organizations of Persons with Disabilities in Flanders.

The Perspective of Service Providers

James Crowe spoke on behalf of **Learning Disability Wales** and gave the perspective of service providers. Mr. Crowe told that 47% of the children with learning disabilities in the UK live in poverty. One reason is that the additional costs of having a disabled child are estimated to £ 7355 per year.³ Among the disabled adults in the UK, 23.7 % are reported to live in poverty.⁴ In Wales, the closure of mental hospitals was completed in 2006 and today more and more persons with disabilities live in their own homes, in supported living or with family/foster homes. Mr. Crowe explained that the main ideology for the group homes in Wales is to characterize people living in them as tenants, rather than home care residents. Their services are provided in line with the five accomplishments: “*contributing*”, “*sharing ordinary places*”, “*being someone*”, “*choice and control*” and “*belonging*”. While inclusion is a goal, it is important to recognize the challenges involved, such as poverty, loneliness, exclusion and

“The challenge for the service providers is to ensure that they can meet the needs of the individual and at the same time minimize the risks that independence brings along.”

James Crowe

complex relations with the staff. In general, persons living in supported living accommodation are living in a protected environment which shields them from facing poverty. However, they are seldom in charge of their own money. Therefore, service providers who support these people often face difficult demarcation problems i.e. it becomes less clear where their responsibility begins and where it ends, for example in managing money. In order to

tackle this dilemma, Mr. Crowe wishes to see a change from the current position of “**wants**” – where people with disabilities have little access to money and a high level of control of the workers, to the position of “**needs**” - with independent arrangement, direct payments and full access to one’s own money. The challenge of this change is to achieve a high level of independence while at the same time minimize all possible accompanying risks. For this, support workers are needed who are trained and able to provide advice and assistance throughout this process towards a more comprehensive personalized care. Finally, Mr. Crowe highlighted an issue that many people with disabilities who live with their families face: that the disability benefit they receive are seen in many families as an important source of income and are used as a part of the family budget. So, while working as a service provider towards greater inclusion and independence of the individual, one must tackle and meet the accompanying challenges with sufficient safeguards.

The Broad Political Context: EU policies to tackle poverty and social exclusion

Ms. Antonia Carparelli, from the **European Commission** (DG Employment) outlined the European strategy to combat poverty and social exclusion. She acknowledged the **2010 European Year for Combating Poverty and Social Exclusion** as an important part in the work of developing policies on poverty and social inclusion. At present, just before the beginning of the new **EU 2020 Strategy**, Ms. Carparelli argued that we have a good starting point to fight poverty and social exclusion, thanks to the European Year 2010 and the **Lisbon Treaty**. While recognizing the difficulties at this early stage to foresee the impact of the Lisbon Treaty, she stressed that the Treaty contains strong values with clear articles on social considerations and anti-discrimination measures which must be taken into account in the production of EU- legislation. These tools will be used in order to meet the big challenge for the EU at present: to lift 20 million people out of poverty and social exclusion during the coming decade.

³ According to the price level in 1992.

⁴ This may be compared to the OECD member state average; 22.0 %

Ms. Carparelli explained that **one of the problems with discussing poverty is the difficulty of defining it**. This became obvious during the consultation among Member States in the creation of the EU 2020 Strategy where the discussion on the poverty target became subject of uneasy controversy. The chosen target is the result of a compromise, and is built on three different indicators.⁵

The financial crisis has aggravated several economic and social challenges such as migration flows, unemployment, poverty, inequality and pressure on health systems. Ms. Carparelli reported that today, 80 million people in Europe live at risk of poverty, 40 million are materially deprived and 45 million live in jobless households. According to Ms. Carparelli, the European Platform Against Poverty, inspired by the Lisbon Treaty and influenced by the political impetus of the European Year 2010, proposes an integrated and innovative response to these challenges. In order to achieve active inclusion policies it is needed to ensure access to services, proper housing and employment with minimum incomes. During the next decade, she held, the EU's aim is to reinforce the social OMC⁶ in order to achieve a more comprehensive cooperation in the work towards the social goals. The EU will further reinforce the capacity to connect different **policies in order to address multiple challenges** e.g. disability and poverty which demands coordination between several policies such as anti-discrimination- and inclusion policies.

*“When the cake becomes smaller –
equity and fairness become more
important”*

Antonia Carparelli

Ms. Carparelli was asked if the seemingly ambitious plans of the EU for the next decade will be able to succeed in these tough economic times when social sectors suffer from governmental funding cuts. Ms. Carparelli replied that **“in the current political reality it is an illusion to believe that the EU has the capacity to change the political agenda of the Member States”**. The EU 2020 Strategy, she said, is a big achievement and a commitment to repair the damages caused by the crisis. However, more data on the link between poverty and disability across Europe is needed in order to measure the efforts needed. Ms. Carparelli further announced that due to limited resources, there will be no increase in the budget for social spending which means that the focus will be to target the most urgent concerns.

Ms. Carparelli further stressed that the social OMCs and now also the **European Platform Against Poverty** will reinforce the partnership between EU institutions and European citizens and make civil society even more visible. Together this creates a **structural coordination with more cross-cutting initiatives** e.g. “inclusion and disability” and “mental health and poverty”.

Due to bad weather, **Richard Wilkinson, professor at Nottingham University and co-founder of the Equality Trust⁷**, could unfortunately not participate at the seminar. Mr. Wilkinson was invited to present research results published in the book **“The spirit level: Why Equality is Better for Everyone”** which he wrote together with professor Kate Pickett. *The Spirit Level* shows that **greater equality in society improves health and life expectancy and dramatically reduces the frequency of a wide range of social problems** such as mental illness, violence, infant mortality and drug addiction. Thus, poverty reflects failures in the redistribution systems in a fair and equitable manner. These failures lead to inequalities which creates a society where wealth is concentrated in the hands of a few while many people are forced to live restricted and marginalized lives. The research presents

⁵ Each Member State will decide its own individual targets and which of the following three indicators are best to define poverty in their country: *relative poverty*, *material deprivation* and *people living in jobless households*.

⁶ The social OMC – the Open Method of Coordination was set up at the Lisbon European Council in March 2000 and provides a framework of political cooperation without legal constraints. Member States agree to identify and promote their most effective policies in the fields of social protection and social inclusion with the aim of learning from each others' experiences.

⁷ For more information, visit the home page: <http://www.equalitytrust.org.uk/>

two main ways of reducing income inequalities: **smaller differences in pay before tax** (as in Japan) or **redistribution through taxes and benefits** (as in Sweden). **Political will** is yet a precondition for successful and effective policies capable of reducing inequalities. What is needed is therefore a wider recognition of how we all suffer the costs of inequality as well as recognition of its influence on social relations –and so to the real quality of life.

Conclusions and Recommendations

A number of thoughts, ideas and questions emerged from the seminar. One general consensus that came forth is that **poverty is not solely a financial concern**; it is equally about emotional wellbeing and quality of life. Poverty brings misery to the lives of many people and constitutes a direct attack on people's fundamental rights. Despite material deprivation, **poverty brings along a day-to-day struggle paved by isolation, stress, discrimination and bad mental- and physical health-condition**. Additionally and as shown by Mr. Wilkinson's study, poverty brings high societal costs and hinders a sustainable economic growth. Altogether, poverty causes vulnerability and social exclusion which leaves the poor in a vicious circle. In order to break this circle and handle the gap between the poor and the society, Mr. Trembos has demonstrated that **understanding** is the crucial tool. Without the involvement and representation of poor people in the process, the missing link will remain present. From the service providers' perspective, this seminar has shown the importance of offering **personalized care** by putting the users at the very centre and provide a high level of "secure independency".

From the EU perspective, ambitious plans were presented by Ms. Carparelli. However, it remains to be seen if these plans and commitments are strong enough to meet the challenge of a Europe where 80 million people are facing poverty, especially so when there are no plans for an increased EU budget for social spending. It is not sufficient to have ambitious plans; they need to be backed up by political will and proper tools if the results they put forward are to be achieved.

Luk Zelderloo, Secretary General of EASPD, closed the seminar with some conclusions and remarks based on the discussions of the day. **First**, he reiterated the general consensus on the need of more research and data on the two-way-link between poverty and disability and what the effects are on families across Europe. This **data is crucial for understanding the multi-dimensional nature of poverty** which demands us to work from several different angles. It is thus needed to measure all issues that capture the poverty complexity: unemployment, poor health, educational disadvantage, the number of people living in inadequate housing and to which extent people live without adequate access to public services. Last but not least, the **gender perspective** needs to be taken into account. Women and young girls face a particular risk of poverty and social exclusion. He also called for more research and knowledge on the relation between poverty and persons with intellectual disabilities since this seminar has shown that they run a lower risk of facing poverty but that they at the same time are not as independent as desired. Finally, research is needed on the link between poverty and institutionalization. In the absence of alternatives, vulnerable people risk to end up in large scale, low quality services. This is particularly the case in the Eastern European countries but it is also a concern in the west. Hence, it is urgent to look at the affordability of high quality services.

Second, Mr. Zelderloo stated that service providers and authorities should focus less on the technical aspects and in addition bring in a focus that recognizes the importance of the emotional wellbeing of the individual. One part of this is to **facilitate self-determination and independence**, which means control over one's own money and at the same time deal with the risks that this brings along.

Third, he identified one key problem that came up during the discussions i.e. the accessibility or rather the inaccessibility to services. One obstacle is the fact that “cultural” differences lead to communication problems which in turn create barriers between people living in poverty and social exclusion and the broad society. Therefore, Mr. Zelderloo emphasized the importance for service providers to “**learn the language of those we want to support**”. One part of this is to involve the people we want to support in the policy- and development processes in a structural and well-organized way.

Fourth, he welcomed the growing understanding on the EU level of the link between poverty and disability. He also called for comprehensive strategies able to make a difference as well as a development of the structural funds to become more focused and target all mentioned problems in a more direct way.



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