



# Conference “Investing in Independent Living”

Sofia, Bulgaria

8 June 2018

## Conference Report

### Joint event

Centre for Independent Living Sofia

European Network on Independent Living

European Disability Forum



Funded by  
the European Union

## Contents

Opening remarks and welcome .....	3
Session 1 – Framework: what is the framework for investing in independent living at the international/EU level .....	4
Ines Bulic.....	4
Robert Jan Uhl .....	4
Andor Urmos .....	5
Lilia Angelova-Mladenova .....	6
Discussion.....	6
Session 2 – From “good examples” to “best practice” – concrete ideas for the types of services and practices that member states should fund .....	7
Pat Clarke.....	7
Iva Boneva .....	8
Rita Leena Karlsson.....	9
Discussion.....	9
Session 3 - action points for future .....	9
Lyuba Derelieva .....	9
Susanne Bosman .....	10
Milan Sverepa.....	10
Summary of the day .....	11

## Opening remarks and welcome

Speakers:

Kapka Panayotova, Director, Centre for Independent Living Sofia

Biser Petkov, Minister of Labour and Social Policy, Bulgaria

- Minister Biser Petkov announced the drafting of a new bill on the rights of Persons with Disabilities.
- The new bill will be in line with the U.N. Convention on the Rights of Persons with Disabilities.
- It will be drafted in close cooperation with organisations of persons with disabilities and improve inclusion, accessibility, ensure high quality services. The bill will also promote a community-based approach and intersectoral cooperation towards de-institutionalisation.
- Funding for independent living will come both from the national budget and from EU funds (European Structural & Investment Funds)



**Ministry of Labour and Social Policy** 🇵🇸 @min\_mlsp · Jun 8

Разработва се проект на нов Закон за хората с увреждания, в съответствие с изискванията на Конвенцията за правата на хората с увреждания. Това съобщи министър Бисер Петков при откриването на Международна конференция на тема „Инвестиции в независим живот“.

Translated from Bulgarian by Microsoft

Razrabtva is a project of a new disability law, in accordance with the requirements of the Convention on the Rights of persons with disabilities. This was announced by Minister Biser Petkov at the opening of an international conference entitled "Investments in Independent Living".



You and ENIL

1- Tweet from Bulgarian Ministry of Labour and Social Policy announcing the taskforce for a new disability rights law

## Session 1 – Framework: what is the framework for investing in independent living at the international/EU level

Moderator: Ines Bulic

Speakers:

Robert Jan Uhl, EU Fundamental Rights Agency

Andor Urmos, DG Regional and Urban Policy, European Commission

Lilia Angelova-Mladenova, ENIL

### Ines Bulic

- Ines Bulic opened the discussion by stating the importance of Article 19 of the U.N. Convention on the Rights of Persons with Disabilities: Living independently and being included in the community. She stated that this article set out the obligation to fund personal assistance and independent living.
- She said that civil society should always keep in mind Article 19 when advocating for strong legislation in line with the Convention.

### Robert Jan Uhl

- Robert Jan Uhl presented the findings of the Fundamental Rights Agency report “[From institutions to community-living](#)”. He stated that it is composed of 3 thematic papers: the first on [commitments and structures](#), the second on [funding and budgeting](#), the third on [outcomes for persons with disabilities](#).
- Key findings of the report include:
  - There is a lack of monitoring;
  - De-institutionalisation commitments only focus on some types of disabilities;
  - The process of de-institutionalisation is managed differently, and by different bodies, in EU Countries. For example, in Spain the process is mostly managed by the Autonomous regions. In Portugal, it’s the local decision-makers that prepare plans that must be approved by regional and national decision-making bodies.
  - Measures to reinforce cooperation between different settings and stakeholders are often missing.
  - Funding often comes from different sources and it’s not coordinated, even intra-country. In France, some funding comes from the regions, some from the national budget. In Slovakia, it is a mix from municipalities, regions, private donors and other stakeholders.
  - E.U. Funds are essential: The European Structural & Investment Funds give crucial support in funding de-institutionalisation in E.U Member States. In
- The third paper details how far we are from fully implementing Article 19. In Bulgaria, 5189 persons with disabilities still live in institutions: 2059 persons with intellectual disabilities, 1022 persons with mental health problems; 1199 persons with physical disabilities and 118 persons with sensory disabilities.
- It also details the way forward: adequate funding and involvement of organisations of persons with disabilities is needed; training programmes on the implications of the U.N. Convention on the Rights of Persons with Disabilities for financing services for persons with disabilities;

reinforcing the capacity of local and regional authorities, with strong involvement of national human rights bodies and organisations of persons with disabilities.

- The report concludes that support must be available regardless of individuals' living arrangements.
- It also concludes that there are severe shortcomings in terms of funding and commitment from EU Member States regarding the process of transition to community-based living: commitments must be clear and funding must be clearly allocated for the process to go well.

## Andor Urmos

- Andor Urmos presented the new proposal for EU's Multiannual financial framework and how it affects funding for community-based services.
- He acknowledged that, in the past, EU funds were misused to support both institutions and bad examples of transition to community-based services. He presented the case of Tantava in Romania, where EU funds supported the refurbishment of an institution, and the case of "community-based" services in Estonia, where small group homes are built far away from towns.
- He stated that "The most common reason for leaving institutional care is death"
- He pointed out 3 challenges in having EU funds for de-institutionalisation: the selection of representatives of stakeholders is often times political, there is a lack of data on institutionalisation in the Member States, and the EU Member States still focus too much on institutions.
- He pointed out that EU member States are not using EU Funds to their full potential when investing in the transition to community based services.
- Regarding the proposal for the Multiannual Financial Framework , Mr Urmos highlighted the main changes. He said that the funds are now more coherent, simpler to use and simpler to combine.
- He also talked about the "ex ante conditionalities". These are the requirements that projects need to fulfil before they are approved. Not supporting institutionalisation was one of the ex-ante conditionalities. This conditionalities are now called 'enabling conditions', which means they will be checked not only before, but also during the project.
- The EU Funds will also have a closer link to the European Semester and be more performance oriented.



"The most common reason from living institutional care is death" shows Andor Urmos from @EU\_Regional . It is unacceptable - this is why it's urgent to fund #IndependentLiving both from #EUBudget and national budgets!

## Lilia Angelova-Mladenova

- Lilia Angelova-Mladenova presented a collection of good examples on Independent Living.
- The examples included a peer support pilot in Estonia; direct payments in Ireland; psychiatric support units in Greece; a mutual support initiative for women with disabilities in Austria; housing and support services in Croatia.
- They also focused on involvement of persons with disabilities. Examples include the development of regional policies in Italy and co-production in the United Kingdom.
- She stated that provision of independent living services should be universal, in order to avoid a “post code lottery”.
- Direct payments are extremely important. Persons can pay for services and equipment to ensure independence. It is in the definition of Personal Assistant that they should be paid by direct payments. Direct payment increase quality of life, as there is the feeling of being in control and how to manage the service. Direct payments are also more efficient: persons with disabilities can use more hours of personal assistance with the same budget.
- Real freedom of movement in the EU is also essential. This means being able to have the same support in all countries.
- She stated the importance of accessibility and having mobile services which can reach remote areas.
- Finally, support and housing need to be available at the same time, but separately. If people are not happy with the services, they should be able to receive different services while staying in the same house and vice-versa.
- It is also essential to not have housing well distributed within the community. Segregation of persons with disabilities by only building accessible housing in one part of a city/town is to be avoided.
- Persons with disabilities need to be involved at every level of these processes.

## Discussion

During the discussion, two main points were worth noting:

- It is possible to use ESI funds to buy (and renovate) already existing apartments in residential buildings. It does not oblige Member States to build new infrastructure.
- Persons with disabilities need to be involved at every level. We need to guarantee transparency of the deinstitutionalisation process. For that, organisations of self-advocates needs funding and disabled people should be provided with support to make informed choices and decisions.

## Session 2 – From “good examples” to “best practice” – concrete ideas for the types of services and practices that member states should fund

Moderator: Kapka Panayotova

Speakers:

Pat Clarke, European Disability Forum/Down Syndrome Ireland

Iva Boneva, Centre for Inclusive Education

Rita Leena Karlsson, former Ombudswoman for the City of Stockholm, Sweden

### Pat Clarke

- Pat Clarke spoke about the Employment Strategy and Legal Capacity in Ireland.
  - He started by explaining the Comprehensive Employment Strategy, and its six strategic priorities: Build Skills; capacity and independence; provide bridges and supports into work; make work pay; promote job retention and re-entry to work; provide co-ordinated and seamless support and engage employers. He also added the key actions: public service employment target raised from 3% to 6%; public service competitions for persons with disabilities; alternative recruitment channels to be put in place.
  - He also pointed out that the strategy is supported by an implementation group, which is independent from the government and is comprised by a range of stakeholders, including persons with disabilities;
  - The plan also includes disability awareness training in government jobs agencies, more accessible processes for job application in the Public Appointment Service, 26 million euros for NGOs and Disabled Persons' Organisations to promote employment of persons with disabilities. The boards of certain state companies (such as transport companies) need to include a person with a disability.
- He also presented the Assisted Decision-Making (Capacity) Act 2015.
  - The act covers a number of arrangements including Assisted Decision -Making and Co Decision-Making.
  - The Act asserts a presumption of capacity – a person does not lack capacity to be a decision maker, but a person may lack the capacity to make a certain decision at a certain moment.
  - Capacity is decided according to the following criteria: understand the relevant information, retain it long enough for a voluntary decision, use or weigh the information, communicate the decision, communicate their decision.
- The act established 3 types of decision-making.
  - Decision-making assistance, where a person considers that their capacity is in question now or in the future for a particular issue or issues and enters into a formal Decision-Making Assistance Agreement which can be triggered when certain specified conditions arise;
  - Co-Decision-Making, where the decisions are made jointly by the person and the co-decision-maker. There needs to be a formal agreement, registered with the Decision Support Service;

- Decision-Making Representative: the Act provides for intervention by the courts where it is believed that a person lacks capacity to such an extent that they require decisions to be made on their behalf entirely by someone else.
- The court in the first instance will assess whether Decision-Making assistance or Co-Decision-Making is appropriate and will only move to appoint a Decision-Making representative after such an assessment.

.@PatClarkeDSI presented #Ireland employment and legal capacity strategies. "There is a presumption of capacity, so a person cannot lack capacity as decision-maker" #IndependentLiving



*Pat Clarke said "There is a presumption of capacity, so a person cannot lack capacity as decision- maker"*

## Iva Boneva

- Iva Boneva started by stating that inclusive education is not only for persons with disabilities. It is equal education for all children.
- She mentioned a study that revealed that 58% of parents in Bulgaria didn't know what inclusive education is. It also showed that 14% of the parents wouldn't want their child in the same class as a student with special needs.
- She pointed that it is particularly important to change the attitude of educators towards inclusive education, especially focusing on implicit bias from the part of the teacher.
- She stated that another challenge is the lack of allocated budget for inclusive education in Bulgaria.
- She then showed an example of a pilot project in Bulgaria – 15 schools are run in an inclusive education model. It was a painstaking process for teachers because it involved realisation that they have responsibility on everything that happens. Therefore, there is resistance from other schools to change.
- She mentioned the need for a procedure to involve parents, so that they can report incidents to school.
- A second model is involved in reducing school absenteeism – they are shown 7 different jobs close to their school. It is focused on schools in disadvantaged regions and for pupils at risk of social exclusion. Truancy reduced by 24%.



## Rita Leena Karlsson

- Rita Leena Karlsson presented the Swedish strategy for de-institutionalisation.
- In 1960, there were 140.000 people in institutions. There were 52 institutions with more than 1.000 persons – mainly persons with intellectual and psychosocial disabilities.
- Legislation forced municipalities to make an individual plan for each person. The plans are inspected by a National Social Board.
- Unfortunately, the number of persons in group homes has been increasing in the last 8 years - from 23.000 people in 2010 to 27.800 in 2017, including 1000 children in group homes. She mentioned that Swedish politicians think that group homes are an acceptable solution. However, this is being met with increasing pushbacks - young people especially don't want to live in group homes.
- Regarding specific support needs, she explained that the law demands that you apply and are approved. However, authorities are increasingly not granting approval.
- Personal assistance was also quite a big issue in Sweden in lead up to elections. In recent years, there has been less support, especially for children under 12 years old.

## Discussion

- Kapka Panayotova said that Bulgaria is not on the same level as Sweden. Sweden ratified the CRPD in 2009 and Bulgaria in 2012, but Bulgaria is lagging very much behind Sweden. She pointed that long-term goals are essential.
- Rita Karlsson clarified how community support services are structured in Sweden. There are public community support services, but also private providers. Persons can choose which provider they want and the municipalities pay. The focus is on paid support, not voluntary support.
- Following a question, Iva Boneva clarified that there was no specific goal in the pilot to improve diversity among teaching staff. She also clarified that there is money for inclusive education but it is appropriated for general education and often misused.

## Session 3 - action points for future

*What legal/policy changes can we expect in the Post 2020 ESI Funds programming period; how can we make sure ESI Funds investments are in line with the Member States' human rights commitments*

Moderator: Dani Koleva

Speakers:

Lyuba Derelieva, ESF and Cohesion Policy, DG Employment, European Commission

Susanne Bosmann, UN OHCHR Regional Office for Europe

Milan Šveřepa, co-chair of the European Expert Group on the Transition from Institutional to Community-based Care

Lyuba Derelieva

- Lyuba Derelieva presented the new European Social Fund proposal for 2021-2027 of 101.2 Billion
- She explained that some amounts were earmarked in the proposal: 25% for social inclusion, 2% for aid to the most deprived, 10% for youth employment in countries with a high number of NEETS - young person who is no longer in the education system and who is not working or being trained for work, and 400 million for outermost regions
- She assured the participants that there was no reduced coverage for the de-institutionalisation process, and that in the regulations it was forbidden to finance institutions.
- The enabling conditions of the European Social Fund include the Convention on the Rights of Persons with Disabilities and the Charter of Fundamental Rights.
- The partnership principle in this period will ensure that social partners, civil society and bodies for fundamental rights are included in the process. She added it was an improvement from the previous Multiannual Financial Framework, as rights advocates and fundamental rights bodies are added.
- The composition of the Monitoring Committees must be publicly available online.
- It was also pointed out that there will be higher co-financing rates for policy innovation.

### Susanne Bosmann

- Susanne Bosmann introduced the paper European Added Value – the [EU Multi-annual financial framework post-2020: a tool to close human rights in Europe?](#)
- She stated that the U.N is strongly pushing for funds to be invested to advance the rights of persons with disabilities.
- She stated that the CRPD Committee called on the EU and Member States to ensure investments go only to community based care.
- She added that a challenge is that de-institutionalisation programs just target some groups of right-holders.
- She added that Member States investments need to comply with accessibility standards

### Milan Šveřepa

- Milan Šveřepa welcomed the commitment to de-institutionalisation that the proposal for the Multiannual Financial Framework showed. He particularly pointed out investment in more support, and voting rights in Monitoring Committee.
- He stated that there is still a lack of initiative at Member State level to use EU funds to significantly improve the rights of persons with disabilities.
- He pointed out that there are still challenges to solve in the involvement of persons with disabilities: examples were the organisation of accessible meetings and a lack of funding for self-advocacy groups.
- He also highlighted the need for better support of persons that leave institutions in their life after leaving the institution.

## Summary of the day

- Kapka Panayotova summarized the day by concluding that under the partnership principle, organisations should invite the people that are most excluded to be part of the project.
- She added that terminology is always a problem, as different parties have different interpretations of accessibility, community-based support.
- There is a lack of understanding of independent living. Some parties understand that it is enough to open smaller group homes.
- It was stated that deinstitutionalisation has still not happened in Bulgaria for the Roma and children and adults with disabilities.
- It was emphasised that not solely the Commission is responsible to find solutions – advocates should actively participate in the process.
- It was positive that the Minister was able to declare readiness of Ministry to effect a substantial change in the disability policy.