

Conference

on deinstitutionalisation in Slovenia

Brdo pri Kranju, 6 May 2014

WORKING REPORT

Key features of the event

The seminar was organised by the Ministry for Labor, Family, Social Affairs and Equal Opportunities in cooperation with the European Commission and the European Expert Group on the Transition from Institution to Community Based Care (EEG). It gathered 240 participants, including representatives from NGOs, Institutions, social workers, users...

Speakers included representatives from Ministry of Labor, Family, Social affairs and Equal Opportunities, President of the Committee of Labor, Family, Social affairs and Handicap, President of the Council, users, as well as representatives of NGOs and of the European Commission. No local authority was part of the panels. The EEG was represented by Jan Pfeiffer (Mental Health Europe) and Claire Champeix (Coordinator).

Jan Pfeiffer, from the EEG, had a preparatory meeting with Slovenian NGOs, most of them connected to European NGOs in membership of the EEG alliance on 18th March 2014. They then met regularly in preparation of this seminar and presented common “starting points” on deinstitutionalisation at the seminar. They expressed the intention of keeping on regular meetings to follow up on the issue.

Presentations and final conclusions of the event are available on the Ministry website:
http://www.mdds.gov.si/si/delovna_podrocja/sociala/mednarodna_konferenca_o_deinstitucionalizaciji/

The proposed evaluation questionnaire was filled by 73 out of 240 participants. To a varying degree, a large majority of them considered that this seminar has fulfilled their expectations (72,6 %), given them important information and knowledge about the use of Structural Funds (69,9%), given them important information and knowledge about the transition from institutional towards community-based services (73,9 %) and that they would be able to transfer gained knowledge into their practice in the future (71,2%) - see attached evaluation report.

The seminar took place in the context of the recent resignation of the current government, with the consequence that no decisive legislative change would be possible in the coming months.

Report of the seminar

Welcome speeches

Representatives from Slovenia institutions made the following points in the opening of the meeting.

State Secretary Martina Vuk, representative of the Ministry for Labor, Social Affairs and Opportunities highlighted the adoption last year of the Resolution on the national social assistance programme 2013-2020 (Re NPSV 13-20) including specific quantitative objectives for de-institutionalisation of adults and the development of new alternatives.

Andreja Črnak-Meglič, President of the Parliament Committee of Labor, Family, Social affairs and handicap reminded the steps already taken in Slovenia towards de-institutionalisation. She highlighted the need for participation of local communities as well as the need to empower users, their families, and ensure the participation of NGOs. She insisted on the need for developing social entrepreneurship and mentioned the drafting of a law on social economy, which will facilitate the creation of jobs in the area of care.

Mitja Bervar, President of the Council of the Republic of Slovenia shared that the Council will, by the end of the year, organise a national consultation in relation to the drafting of legislation on Mental Health. He stressed the problems associated with institutions, including their cost. Though, he stressed that austerity should not be the driven force for reforms, but rather the fact that the level of democracy of a country is to be judged against its attitude towards the most vulnerable.

Session I: key notes presentations

Jan Pfeiffer (Mental Health Europe Senior Policy Officer- EEG) explained the change of paradigm implied with the transition from institutional to community based care. He gave an overview on the situation with regard to deinstitutionalisation in the European Union and presented an analysis of the strengths and weaknesses of Eastern countries in relation to this needed reform. He then went through the risks and fears associated to deinstitutionalisation and shared key principles for a successful process.

Claire Champeix, Coordinator of the EEG, presented the group – an alliance of NGOs, Foundations, public and private services providers, international organisations – joining forces to ensure that alternatives are developed. She detailed activities led by the group with the support of the European

Commission and how these can support a national deinstitutionalisation reform. She presented two tools produced by the EEG in the objective of supporting stakeholders to implement deinstitutionalisation reforms. The Common European Guidelines on the Transition from Institutional to Community Based Care and the Tool Kit for the Use of European Funds for the Transition from Institutional to Community Based care are based on ground experience as well as on an extensive consultation with relevant experts and practitioners (see <http://deinstitutionalisationguide.eu/>).

Jader Cane, Deputy Head of Unit at the Directorate General for Employment and Social Affairs in the European Commission, presented how the European Structural and Investment Funds (ESIF) supports the transition from institution to community based care.

He stressed the crucial importance of taking advantage of the current period to make the best use of ESIF to support deinstitutionalisation. Regulatory instruments are being negotiated that will apply to the spending of important budgets likely to push forwards reforms and support deinstitutionalisation for the next seven years. Negotiations take place within a reformed regulatory framework providing a series of important hooks to support the transition from institutional care to community-based care. In addition Slovenia has received specific advice in this direction by the European Union. A country Specific Recommendation in the framework of the Europe 2020 Strategy advises to "*... Contain age-related expenditure on long-term care and improve access to services by refocusing provision from institutional to home care, sharpening targeting of benefits, and reinforcing prevention to reduce disability/dependency.*" **In their position paper the European Commission also insisted on the need "to enhance access to affordable, sustainable and high-quality services, including health care and social services of general interest**", including "supporting the transition from institutional to community-based care and services, especially in child, rehabilitation, mental health and long-term care".

He stressed that stakeholders have the knowledge that can improve the programming and help to make it possible to success in implementing the reform. He concluded on the need for partnership with competent regional and local authorities, as well as other relevant stakeholders.

Vito Flaker, Associated Professor at the University of Ljubljana, Faculty of Social Work, presented an overview of the deinstitutionalisation process in Slovenia.

He insisted on the fact that, despite a number of breakthroughs, Slovenia is still an institutionalised country in comparison to others. He presented the history of innovative approaches developed in Slovenia since 1967. Positive results have been achieved for reducing the number of residents in re-education institutions for young people in the 80', but has not been followed up.

He pointed out the lack of monitoring of the past attempts, and the lack of focus on person's needs, as well as the fact that the ultimate step of deinstitutionalisation, i.e. democratisation and independent living of residents, has not been achieved. Through these past experience, deinstitutionalisation has only became a complement not a replacement to institutions.

Vito Flaker concluded by focusing on the following key points:

- The power relation between experts and users is important to their life environment;
- Persons should be empowered to live their own life, not the life others created for them;
- We need not only to prove some results but to allow for people to live a better life themselves;

- In itself, exiting an institution can empower and enable people to live an independent life.

Susana Oreški, from ALTRA presented how NGOs in Slovenia moved “from innovations to community based care programmes”

She recalled the advocacy work done in the 90' to raise public awareness about the fact that institutions are not adapted to individuals needs and are associated with human rights' infringements.

She presented how, for more than two decades, an assistant support model in the community has been developed, based on the work of outreach organisations helping people in their environment, and regretted that institutions have not been closed in parallel. Since 1993 social networks, clubs, activities, advisory services, creative workshopsincluding people with mental health problem have been created around 32 day care centres. This programme is funded by the Ministry, Foundations, and Municipality of Ljubljana. What was an experimental programme is now turned into verified.

In 1990 the first rainbow society residential group opened and represented the first attempt of this kind.

In 2005 a coalition of NGOs in the field of mental health was set up.

Susana Oreški stated that this social assistance programme and model should not be pushed on the margins of the social care system but considered of strategic importance.

Susana Oreški also shared that all NGOs are gathering in a Platform for following up the deinstitutionalisation process. They agreed on the following starting points, stating that deinstitutionalisation process should:

- Enable people to live a sovereign and independent life;
- Involve users and families in the decision making;
- Adjust to the needs of individuals;
- Comply with human rights;
- Empower users.

SESSION II – Discussion panels

First panel : the point of view of users

Three users of institutions and services strongly testified of the failure of institutions as well as of the weaknesses of the support to independent living, building on their experience as adults suffering from disabilities but also as children who experienced life in institutions.

Emir OKANOVIĆ lived in a series different institutions for the education of children with disability and eventually managed to live in his own flat through the support of Soncek organisation.

He insisted on the difficulties I went through to be able to study and to work, due to the lack of adequate status as well as social protection.

He insisted on the poverty lived by people who have to live on a disability benefit set at 400 euros, when 600 would be a minimum to survive. He called for adequate financial support for those who succeeded in living by their own. "*We have to live what we talk*" he concluded.

Aldo TERNOVEC shared the point of view of an association of pensioners (SDUS). He first insisted on the wish of the elderly to remain active in their environment and to be useful to their family.

He then focused on the situation of many elderly people, not in institutions which they can't afford, who remain at home without any specific assistance due to the lack of services. This problem is particularly accurate in remote rural areas. A survey organised by his organisation shows that 65% of the elderly help their family. They often experience burn out, and the quality of the support they are able to provide can be questioned.

He made a call for informal care providers and care takers to receive more attention.

He concluded by stating that he, as the wide majority of pensioners, wants to stay at home and live a quality and active life at home as long as possible.

Mijo POSLEK shared his memories of bad treatments received as a child in an institution for children with mental health problems – he received electroshocks, was put in a cage...

Though today, with support, he lives in Ljubljana and can experience freedom in his life: for example he can go out with friends and go to the sea side, which means a lot to him.

Zdenko ŠIBAV represented an organisation of relatives of persons with mental health problems who have been advocating for deinstitutionalisation. He said he knows that it is not going to be a "cheap and easy" process. NGOs will keep an oversight of developments of this reform.

He stated that, from a legislative point of view, the national programme for Mental Health goes in the good direction, but immediate legislative support is still lacking (for example the law on Mental Health lacks implementing regulation). He insisted that closing institutions should go in parallel with developing other supports and community based services.

He also insisted on the need to devote funding to the education of relatives, as well as to support them in order to avoid their burn out.

Violetta Bilak was very emotional about the story of her life she accepted to share - which made her an activist.

Violetta Bilak was diagnosed handicapped when she was three years old, then placed in a hospital since it was impossible to access rehabilitation and education in the place she was born. She was overwhelmed with anxiety, her relations with her family were very scarce and she suffered a lot. When she refused to eat she was given injection and sent to a correction home.

At some point she saw no meaning in life. Now she is fully assisted for years and lives a useful and beneficial life. But she said she needed seven years of intense reading to change her destiny and overcome what has been left to her in the past.

She wants her experience to testify that no children should be torn apart from their family; that they all together should be assisted. "*Independent life with the help of assistant is our right*" she stated.

Though she regrets that, in her words, nothing changed since her childhood. She reported the example of a friend given nappies whereas not incontinent because she has been placed in a home for elderly people!

In a short **discussion** following these presentations the followings points were raised:

- Institutions should train residents to be able to leave;
- Municipality should create the conditions for independent living;
- People who move out of institutions are confronted with precarious economic conditions;
- A law on long term care should be adopted.

Second panel : the point of view of the government.

Nadja Čobal, State Secretary, represented the Ministry for Health.

She mentioned that the Ministry of Health wants to develop an action plan.

She recalled the adoption of a law on mental health in 2008 with the support of NGOs and considered that it is the best possible strategic as well as legal base for implementation of community based care. She added that, due to the current political situation, it was not clear still how the implementation will be organised and funded.

She mentioned an experience of Community psychiatry concerning 293 patients in Idria which gained positive results and resulted in people concerned being left often hospitalised than other with comparable needs. She stated that the number of beds in psychiatric institutions should be reduced and community psychiatry developed.

Nadja Čobal, then raised the issue of regional differences with regards to access to health, and stated that these differences cannot be tolerated. She explained that monitoring was implemented so that equal access to health was allowed to all habitants.

She finally came to the issue of long term care and mentioned that the Ministry was thinking of setting up special services in addition to the draft national programme.

Aljuš Pertinač, State Secretary, represented the Ministry of Education, Sciences and Sports.

Aljuš Pertinač, mentioned a law on education on special needs in preparation. This law envisages the setting up of a consultative body, gathering experts as well as practitioners from several fields, which will assist the decision making for the period 2015-2025.

He explained that 360 children with severe health problems and special needs live in educational institutions in order to benefit from education as it is not possible for them otherwise.

Children may be placed in this institution by decision of justice or social services, because of their health problems and the poverty of the family. Though the number of children in educational institutions tends to fall. The Ministry aims at supporting these centres.

Aljuš Pertinač mentioned a working group in the Ministry on children with special needs.

He pointed out in his conclusion that they now have to wait for the new government before going further.

Martina Vuk, State Secretary, represented the Ministry of Labour, Family, Social Affairs and Equal Opportunities.

Martina Vuk reminded that the resolution adopted in the Parliament clearly specifies the need for transition. She insisted that conditions must be provided for enabling inclusion of vulnerable people.

She explained that the Ministry was still working on the law on long term care and personal assistance but this cannot be adopted in the next six months due to the change of government.

She made the wish that, with the support of Structural Funds, other forms of assistance outside of institutions can be developed.

She pointed out the importance of a meaningful consultation, including users as well as their relatives.

She concluded by stating that barriers in our heads are the most difficult to overcome.

Questions and answers

Nace Kovač first summarised the main issues. He raised the need to foster reform and cooperation between stakeholders, to build on good examples and ensure a change in the mind sets. He highlighted the lack of resources of people out of institutions and pointed out that there was still no plans to close some institutions as well as plans to refurbish new special schools.

Nadja Čobal explained the projects of the Ministry for Health regarding an institution in Stara Gora, where children and young people under twenty six from the entire Slovenia as well as other countries live. She explained that this institutions has changed, and now gather twenty five children which he considered as an optimal number. The plan is to renovate the building, reduce the number of beds and prepare to other forms of assistance

Aljuš Pertinač, for the Ministry of Education, presented the situation of an institution in Ptuj Pertinac, which is being rebuilt.

Thanks to an agreement with the local community the building to be finished within one year. The majority of children concerned are included in mainstream schools and get assistants but there are also children with severe disability -according to criteria defined by law- for which the situation is different. He added that nobody from the school or relatives ever asked for closing the institution.

Martina Vuk explained that one objective in the national programme is to reduce by 50 % the capacity for adult by 2015. The adoption of the law is linked to the reform of Health Care which is still in a status quo currently.

These presentations raised strong reactions from the audience. Klaudija Poropa (Institute for the theory and culture of disability) said "*twenty five is a still a lot if you are living in such institution*" she said – "*Even with a new roof, this is still an institution*". She reminded having been kept in bed all day long

when she was living in Stara Gora. She demanded that money is made available not for institutions but to allow these children to access NGOs provided services. She reminded that no job is created within NGOs providing these services recently. She questioned the way policies as well as tender are organised.

A participant pointed out that 30% of the amounts paid to people providing assistance and care returns to the State through the taxation system.

Nace Kovač concluded by stating that the demands and criteria from European Commission were clear and hoping that solutions will be commonly achieved. Parallel workshops were organised in the first part of the afternoon.

Final plenary

Rapporteurs from the workshops presented the following points.

1. Workshop on children and youth

- Deinstitutionalisation is a matter of culture and solidarity.
- Since the United Nations Convention on the Rights of Persons with Disability has been signed by Slovenia, all citizens should be informed.
- It is important to prevent institutionalisation and provide support after placement.
- The focus should move from medical aspect to the social aspects, including barriers to inclusion into community life.
- Children should not be divided on the basis of their disability. Every child should have the possibility to go in his primary community school. Such an approach will also accelerate deinstitutionalisation for all ages.
- Community based services should be accessible for all.
- Users should have their say regarding the services provided.
- Cooperation is needed at the inter-ministerial level but also within the Ministry between various departments in charge of Labor, Social Economy.... This is the only way to absorb the potential of the Funds and fulfil the needs of the people.

2. Workshop on adults

- The reform of the care system is a much needed political decision. Institutions are no longer an option and we cannot continue to invest in institutions.
- We need a clear strategy with clear defined objectives.
- Such a strategy can only be successful if enshrined in the next programming phase.
- Experience gathered in the EEG can be shared usefully with Slovenian stakeholders.

- A legal base is needed for deinstitutionalisation in all categories. Existing law should be amended.
- The homeless and the imprisoned should be included in the process.
- The lack of services available in the community should be addressed, and new jobs developed.
- Users must be involved at any stage of the process and not only their representatives.
- Participation of the whole local communities should be ensured.
- *"A Institution is not only a wall but a situation of lost control over your life which is managed by others"*

3. Workshop on the elderly

- Community based care is needed for allowing people to stay at home as long as possible.
- A transformation of institutions should be more efficient to ensure variety of modern community based programmes which will reflect all forms of deinstitutionalisation.
- Networking between professionals and voluntary carers should be intensified and profounded
- New forms of long term care should be developed with an emphasis on vulnerable groups.
- Complete model of assistance support (training, supervision,..) should be offered to all care givers including informal care givers.

Concluding remarks

Jan Pfeiffer explained that Jader Cane apologizes for having to leave before the final session, and presented the shared point of view of both the EC and the EEG. He described deinstitutionalisation as a long process, mentioned that there were still a number of Institutions in Slovenia and that priority was not given to deinstitutionalisation in the way the money was allocated. He regretted that the conference did not give the possibility to exchange more with Institutions as well as local authorities. He insisted on the current programming period as a unique opportunity to consider how to use ESIF for deinstitutionalisation and fulfil the Slovenia ambition to halve capacities of institutions by 2020. He added that, in order to fulfil such an ambition, national and regional plans would be needed and that the European Commission as well as the EEG were ready to assist.

Martina Vuk considered that some consensus have been built through the day, providing a solid basis and renewed commitment for a continuing process in the future. She presented some draft conclusions that were due to be finalised and published by an ad hoc working group in the coming weeks. These conclusions included:

1/ Key principles for developing deinstitutionalisation in Slovenia:

- Appropriate planning, involvement of all stakeholders and efficient use of structural funds are key for developing capacity building and deinstitutionalisation,
- Users and relatives must be involved;
- Services providing flats should be involved;
- Empowering of users should be a priority;
- Children with disability should be admitted in mainstream schools;
- More community based services should be developed for people with special needs;
- Solidarity should be developed within the communities.

2/ Concrete conclusions with direct impact:

- The existing legislation should be amended(supplemented);
- A new legislation on long term care should be drawn up;
- A concrete action plan should be drawn up and harmonised with the regional level;
- Clear priorities, as well as follow up indicators should be set up;
- A body should be set up to monitor the involvement of the representatives of users, providers, local authorities and other relevant stakeholders;
- Steering committee should be set up at national level;
- Training should be offered to informal carers;
- A call for proposal should be issued to encourage new form of community care.

Nace Kovač agreed with the draft conclusions and concluded by stating that Slovenia has entered a concluding phase of something that started in the past. He thanked all the participants and specially EU who came from abroad.

This report has been drafted by Claire Champeix, Coordinator for the EEG. Note that its contents doesn't necessarily reflect the views of each organisation in membership of the EEG.



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