



MEETING REPORT

Social and Health Care Services Network

Paris, 10-11 October 2018 hosted by Fédération de l'Entraide Protestante

Wednesday, 10 October

Jean Fontanieu, the president of <u>Fédération de l'Entraide Protestante</u> (FEP) welcomed participants and gave a short overview of FEP and its activities. He specified that in the network, 120 different organizations are specialised in elderly care gathered under an alliance "Alliance des EPHAD Protestant" chaired by **Michel Gadreau**.

Then, Galina Poliakova from Age Concern Ukraine (Turbota pro Litnoh v Ukarini) gave a short devotion.

After the devotion, **Alexander Elu**, Policy and Membership Officer at Eurodiaconia, welcomed participants to the meeting of the Social and Health Care Services network and introduced the agenda. Next, participants had the opportunity to introduce themselves and their organisations.



Michel Gadreau – The French context: an overview of the situation of long-term care and the role of faith-based providers of services

The first session was dedicated to an overview of the French context and the situation of long-term care. The speaker, **Michel Gadreau**, president of the Alliance of EHPAD (Residential care for elderly dependent people) focused his presentation on the state of residential care for elderly people in France. He explained the

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complexity of the French system and the different layers of decisions with an impact on nursing homes for elderly people. The French system is composed of three main levels: the national level, the regional one and the local one.

The ministries at national level define the orientation of health care policies as well as budgets. The Health Regional Agencies pilot health policies in the regions and adapt them to the regional context. **Michel Gadreau** stressed that it is with the regional agencies that nursing homes negotiate the multi-annual contracts including the budget. However, not all budget is defined at regional level as departments (the local level) also allocate some funds. For **Michel Gadreau**, such a division renders budget negotiation difficult for nursing homes especially when the different government levels have conflicting political priorities.

Nursing homes for elderly people at local level are subject to the orientation given by the national and the regional level. For instance, the regional level is pushing for the development of telemedicine as an alternative to the lack of medical specialists in various areas of France.



Michel Gadreau, Alliance of EHPAD

Michel Gadreau stressed how such a complex governance structure represents a burden for service providers, who are accountable to the different government levels. For instance, they are asked to monitor a wide range of quality standards that should be implemented by all establishments. If the provision of quality services is essential **Michel Gadreau** stressed that the quality standards are so detailed that they lack the capacity to assessing them all.

Michel Gadreau also described the difficult context faced presently at nursing homes due to the lack of staff, hard working conditions and the bad image of the residential care in media. However, he stressed that staff members of residential care work with great commitment on a daily basis to provide the adequate care to elderly people in nursing homes.

After the presentation, some participants shared the context in their own country. For instance, **Anna-Liisa Arjama** from the Helsinki Deaconess Institute explained that in Finland there is a national push towards homecare and a decreased support towards residential care as a result. Then, the discussion focused on quality standards. Different participants were keen to know the number of nursing staff per person in the residential home care. **Sylvie Dupont**, from the Salvation Army in France, shared that the ratio in France is 5 nurses for 100 patients, which is not enough.





Study visit: La Muette des Diaconesses de Reuilly, care home for elderly people

The afternoon was devoted to a study visit to the <u>Diaconesses de Reuilly Care Home</u>, a residential care facility hosting 88 people in its full capacity. The average age of residents is 87 years old and the dependence of residents vary greatly. Most of the rooms are single rooms and residents can bring their own furniture with them. The residence also provides a couple of double rooms. Activities for residents are organized on a daily basis, who can also enjoy the garden and go to the chapel.

The Eurodiaconia delegation was welcomed by the director of the care home and by its Pastor **Deborah Huber Mc Bride**. Participants visited the facilities and learned about the organization of the nursing home and the vision behind it.



Diaconesses de Reuilly Care Home

Thursday, 11 October

An Jacobs – Digital support in self-management of people with multiple-chronical diseases: reflections from the H2020 ProACT pilot in Belgium

The morning of the second day began with the presentation of the <u>ProACT pilot project</u> by professor **An Jacobs** from the Vrije Universiteit Brussel, a researcher for the project. ProACT is an integrated technology systems project for Pro Active Patient Centred Care funded by Horizon 2020. **An Jacobs** explained the need to develop integrated care in Belgium as the care system is deeply fragmented between primary care, secondary care and tertiary care. In 2015, a top-down approach was launched at national level with the Belgian Plan "integrated care for better health". After that, a bottom-up approach with a pilot project such as the ProACT project on integrated care for people with multiple-chronical diseases has been developed. The project started 8 months ago for a period of 4 years.

An Jacobs shared that one of the most important messages regarding integrated care is that there is no one size fits all solution. The needs of people must be deeply understood; therefore, such a project should focus on one specific population. Taking that into account, the ProACT project focuses on people with multiple-chronical diseases and with a minimum of ability to use digital tools.

The aim of the project is to develop a digital support to persons with multiple-chronical diseases. The objective is to connect the person to a digital platform getting all data together, collecting them and analysing them. To this aim, the digital platform consists of a personalised interface through which patients can monitor their symptoms. Information is sent automatically to the platform. Furthermore, the personal network of users is included in the project as users can give access to their family to the platform. A dedicated Belgian team of 5 persons monitor the alert, take actions and follow up from Monday to Friday.









An Jacobs, Vrije Universiteit Brussel

The ProACT project is currently in a trial phase. During this phase, a participatory approach is being used to involve users at all stage of project development.

Some learnings can already be drawn from the first trial phase. There is a lack of awareness of strategies for self-management; there is a need to support people in the learning track and the use of the device can have huge impacts on lifestyles, relationships and psychological well-being.

The only equipment needed for participating to the project is a watch and internet which make it accessible for many people. However, **An Jacobs** explained that they still need to be more precise on the users who are able to use the device or not.

After the presentation, **Anna-Liisa Arjama** shared that she can see the importance of the device to give more place to the relation between users and practitioners because time on data collection does not need to be spent during the meetings face to face. **An Jacobs** added that with the use of the platform, people are more aware of their health and can decide the extent to which they want to be involved in the process. However, according to her, the device is not for everyone because some people can get really anxious about it. For **Peter Bartmann**, it is an interesting system for people who are heavy users of the medical system but agreed that the device may not be suited for everyone.

Romana Belová – Q-Europe project on quality management in long-term care (video)

The following session was dedicated to the topic of quality in long-term care. In her video address, **Romana Belová** from Sleszka Diakonie presented the Q-Europe project on quality management in long-term care. Slezska Diakonie is the lead partner of the project, which is mainly aimed to support the promotion of long-term care through a broader understanding of quality principles among staff and stakeholders. The project is developed around several objectives: a learning process (through sharing and the development of a handbook for managers); the training of staff members thanks to the Q-handbook; the sharing of best practices and knowledge; and the dissemination of the project outcomes.

Romana Belová explained the importance of the Eurodiaconia network for sharing best practices and knowledge.

Both short-term and long-term results are expected from the project. On the short term, the project will give an overview of quality management systems in Europe and describe the challenges of key quality principles in long-term care services. On the long term the project will design, implement and run training activities supporting education in quality management systems in long-term care services in other European organisations. These objectives should contribute to the promotion of quality of life standards among elderly people.





Romana Belová concluded by describing the seven quality principles that are being developed in the ongoing handbook: the respect of users' rights; participation and empowerment; accessibility; person-centred approach; comprehensive; continuous and outcome-oriented approach.

After the video presentation, a discussion around quality standards and their meaning followed. For **Anna-Liisa Arjama** the handbook could represent a useful advocacy tool towards politicians. **Peter Bartmann** raised the concern of the differences in quality standards between care provided at home and care provided in residential settings, which is generally easier to monitor. For **Olga Starostová** the handbook can also be helpful to develop a self-evaluation of quality within each organization. In this way, a quality label could also change the thinking of carers and their approach of service provision toward more quality for the elderly people.

The next and last session of the morning was dedicated to project presentations by members.

Anna-Liisa Arjama – Senior Vamos: reaching out to older people living at their homes for meaningful and dignified everyday lives

Anna-Liisa Arjama from the Helsinki Deaconess Institute (HDI) began her presentation by stating the vision behind the work of HDI: the right to dignity for everyone.



Anna-Liisa Arjama, Helsinki Deaconess Institute

The <u>Senior Vamos project</u> is a flagship project run by HDI since 2013 in three different cities: Helsinki, Tampere and Espoo. It identifies and helps elderly people in challenging situations and left outside the public service system.

The project especially focuses on elderly people in need of deep care. As in Finland the provision of social services is good, the project is not a life time-support project but rather a temporary help for elderly people to get support from public services.

The project combines the work of professionals who assess the situation of elderly people (one from the municipality and one from HDI); and the work of volunteers and students who spend time and help elderly people at home. **Anna-Liisa Arjama** explained that a good cooperation with educational institutions has been developed, especially with nursing schools as being involved in the Senior Vamos project is a good practical experience for nurses. Volunteers and trainees work independently but have the support from the two employees in each project.

Participants were keen to know more about the cooperation with the municipality on this specific project. **Anna-Liisa Arjama** explained that the municipality was involved from the beginning of the project, since the application. One participant asked if the demand for this project was not too high compared to the supply of services. **Anna-Liisa Arjama** replied that the focus is only on the most vulnerable ones, those who are deeply excluded, with no family to help them. In this way, excess demand is avoided to a great extent.

Anna-Liisa Arjama next touched upon another project: the Sanenvakoti home providing accommodation for 48 people with dementia, for 5 young men with alcohol and drugs problem and for 24 healthy students. The 24 students occupy the top of the building in exchange of a cheap rent. Also, they volunteer for 10 hours every month with the people with dementia. The staff of this facility wear street clothes and have meals with the people with dementia to reduce as much as possible the difference between carers and residents. Furthermore, there are no specific times for visits and residents have their own keys.





Magdalena Grünbecková – Support for family carers

Magdalena Grünbecková, regional project coordinator at <u>Diaconia of the Evangelical Church of Czech Brethren</u> (ECCB) began her presentation by explaining the situation of family carers in the Czech Republic. They have little public support, poor access to social benefits and many need to quit their jobs because they cannot reconcile these with their care burden. Based on these observations, Diaconia ECCB launched the project "support for family carers" in 2006. Since 2013, the project has been scaled up to all regions of the country.

The objective of the project is to provide necessary support for caring families through advice, information, legal orientation, training and psychological support. Five different activities are developed: educational programmes and courses; supporting and experience groups (self-help groups and experience groups); personal counselling (in hospitals, in various social organisations but also in the carer environment); a call centre (open every week-day); and handbooks and training videos.

Olga Starostová – The work of the Institute on Dignified Ageing. Diaconia and the concept of integrated care of elderly in the Czech Republic

Olga Starostová is a researcher at Diaconia ECCB and presented the work done by the Institute on Dignified Ageing Diaconia in the Czech Republic. The Institute was established in 2013 and aims at changing widespread views of society on ageing and dependency to bring innovations and support informal care givers. The Institute has two main workstreams: Care at Home and Stay at Home. On the workstream Stay at Home, the Institute has developed projects around the model of integrated community care at local level and focuses on the municipalities. Olga Starostová explained that in the Czech Republic the law is very vague regarding the duty of municipalities towards elderly people and the demand of social services is very fluctuating. In the view of the Institute, the role of municipalities is key to develop a model of integrated community care at local level. Therefore, since 2017 the Institute has developed a pilot project in three towns in three different regions. In each region, the idea is to have a local coordinator supporting ageing people in need. The coordinator is an employee of the social department team at the municipality who works full time to support elderly people and their families. One of the main aims of the project is to make services accessible for all elderly people in the town.

Olga Starostová concluded her presentation by inviting the participants to attend the Institute's conference in Prague on November 28 on "Ageing at home, ageing in community".

Anne Filali - Services for people with disabilities at Caritaslaiset

Anne Filali from <u>Caritas Finland</u> Evangelical Lutheran Diocese in Oulu focused her presentation on long-term care for people with disabilities. She emphasised the need to stress the enabling role of social services for people with disabilities rather than the idea of care. Indeed, services help people with disabilities take their own decisions, participate in everyday life and become integrated with society. The services and support provided vary greatly depending on the need for assistance of people with disabilities. Caritaslaiset provides a wide range of such services, including housing services, activity centres, personal assistance services and employment services.

Anne Filali first focused on Caritas Homes for people with disabilities. One of the house units, <u>Kippari</u>, has been built for people with learning disabilities. From the beginning, residents have been involved in the development of the house unit for example in choosing the location of buildings and the colours of rooms. Because of residents' choice, the Kippari house (composed of 5 units for 25 residents) is located next to the university and to a shopping centre. In that way, residents can take part in the activities of the city like everyone else. Indeed, some residents live very independently, even if they rely on Caritas services, staffing and guidance.





Then, **Anne Filali** presented a house unit dedicated to physically disabled people, the <u>Caritas Celesta</u>. Residents of the unit are supported by therapists who assist users in their participation in a wide range of social activities. However, not all residents of Caritas houses are able to take decisions. Therefore, specific homes for people with high support needs also exists. For example, the <u>Maininki Residence</u> is composed of 5 homes of four people where each resident has his/her own apartment but has also access to common areas and services are available 24 hours a day.

Finally, **Anne Filali** presented Caritaslaiset project supporting the employment of people with disabilities. The project "<u>Job for real</u>" is funded by the European Social Fund and aims to enable the employment of people with disabilities in Finland and change the attitude of other employees toward their colleagues with disabilities.

Galina Poliakova - Training sessions on dementia and support for the community

The <u>Ukrainian Charity</u> Turbota pro Litnih v Ukraini (Age Concern Ukraine) was created 19 years ago in order to protect the rights and interests of older people. **Galina Poliakova** began her presentation by describing the Ukrainian context, where 22% of the population is over 60 years old.

The Ukrainian Charity works in 9 different localities and most of its work is supported by senior volunteers of more than 65 years of age. The work of the Charity is developed around different actions: advocacy, home care, street actions, training sessions and older citizens monitoring. Volunteers are active with elderly people, they meet the elderly in their houses, spend time with them, read them books or go shopping together.



Galina Poliakova, Turbota pro Litnih v Ukraini

Galina Poliakova also explained that they try to work in East Ukraine, near the war area whenever it is possible. In this area, people have almost no access to shops or services and deeply need help and support.

To conclude, **Galina Poliakova** shared that one year ago they began a project in cooperation with Diakonie Austria on the topic of dementia. The activity of the project is to organise training sessions in nine Ukrainian cities for carers, family members, volunteers, school teachers or district police officers on the topic of dementia. She stated that working with school teachers was important as changes come through education.





Borka Vrekic - Home Care Services in Serbia

In Serbia, homecare is the most common form of social services for the elderly. The <u>Ecumenical Humanitarian</u> <u>Organisation</u> (EHO) runs 9 Home Care centres in Serbia and holds a running Home Care licence that is renewed every 3 years.

Borka Vrekic, project coordinator of homecare, explained that homecare activities of EHO are publicly financed through a competitive tender process. As a result, EHO is an important non-for-profit provider of Home Care services in Serbia. However, according to **Borka Vrekic**, the provision of such services is still dominated by the public sector and competition is the biggest challenge to their work. EHO tries to make continued improvements to the range of services offered and has recently equipped itself with a socioeducation and a therapy room.

To conclude, **Borka Vrekic** shared that EHO aims to become an association of licensed service providers in Serbia. A major question for them is whether the private, for-profit sector should be included in this partnership to gain a greater access to public procurement procedures in spite of significant differences in terms of goals and mission.

Policy workshop: the European Pillar of Social Rights: from rights to reality

The last session of the network meeting was dedicated to a workshop on the long-term care in the European Pillar of Social Rights. **Alexander Elu** gave a short introduction on the European Pillar of Social Rights and especially focused on principle 18 on long-term care. **Alexander Elu** explained that the European Pillar of Social Rights aims at making social rights effective and promoting upward social convergence in Europe. Principle 18 focuses on long-term care and includes the right to everyone to affordable long-term care services of good quality, in particular home-care and community-based services.

After the short presentation, **Célimène Bernard** divided participants in two groups and presented 3 questions they had to reflect on:

- Is the 'right to long-term care' enshrined in national legislation? How is such a right not enforced/breached in practice?
- According to you, what is missing in the definition of principle 18? What can be improved at the implementation stage?
- What would be the main challenges in your country/for your organization in order to bring the principle into life?

Outcomes of the discussion

Participants shared that the right to long-term care is legally enshrined in many of their countries. They stressed that the inclusion of family carers was missing in the definition of principle 18. The group also identified the difficulty of influencing local governments in order to implement the principle.

Other missing points in the definition of principle 18 were mentioned: the definition of key concepts such as the meaning of quality; the accessibility of care; and the inclusion of personal choice. Among the challenges, participants mentioned the high level of bureaucracy, the lack of recognition of the place of elderly in our societies, the lack of capacity and the difference between theory and practice.

Alexander Elu concluded the Social and Health Care Network meeting by thanking all participants for their active participation and invited them to participate next year's meeting, which will take place in Oulu (Finland) in November 2019.