



MEETING REPORT

Healthy Ageing and Long-Term Care Network (HALTC), hosted by Diaconia Valdese

Torre Pellice, 5-6 October 2016

On 5-6 October, over 15 participants from Eurodiaconia member organizations gathered to discuss long-term care issues faced in care practice and their relation with EU and national policy frameworks. The conference was hosted by our Italian member, Diaconia Valdese, and welcomed participants from Italy, the Czech Republic, Slovakia and Serbia.

The discussion focused on issues and good practices around ageing and elderly care, with specific attention to integrated care and homecare. The meeting also discussed future action on mental health.

Wednesday, 5 October 2016

Victoria Munsey, Vice-President of Diaconia Valdese CSD and member of the Eurodiaconia Supervisory Board, welcomed participants and conducted a devotion touching on service and caregiving drawing inspiration from the words of Matthew 25:31-46.

Alexander Elu, Policy and Membership Development Officer at Eurodiaconia, next presented the agenda and thanked the host organisation and participants, who had a chance to briefly introduce themselves and their work.

The first session illustrated the situation of care services in Italy and the Piedmont region, where Diaconia Valdese concentrates the majority of its services. **Giovanni Comba**, President of Diaconia Valdese CSD illustrated the areas of activity of Diaconia Valdese and framed the history of the Waldensian Church, Italy's main protestant community.

The Waldensian movement started in the alpine valleys of western Piedmont and joined the Calvinist reformation in 1532. As a result of this, the Waldensians faced prosecution and exile during the Counter-Reformation. In 1848, they were finally recognised and granted civil rights. The Waldensians interpret the biblical call to service as one of the two pillars -together with preaching- of the Church, putting their faith on inclusiveness and relationship-building. The services provided by the Waldensians reach people of all faiths, and range from children, unemployed youth, adults in difficulties, elderly people, disabled people and refugees and asylum seekers. Cooperation with a wide range of NGOs and local organizations is also pursued.

Since the 19th century the Waldensians have been active in residential facilities concentrated mainly in the Waldensian Valleys but also in Florence, Bergamo and in Vittoria (Sicily). Attention to training of staff, as well as the involvement of local and foreign volunteers, help ensure a good quality of life for residents. However,

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the demographic challenges faced by Italy -in the last 35 years, the number of persons over 65 years old rose by 50%, while the number of persons over 80 rose by 150%, has prompted the CSD to adopt a strategic approach to guarantee the sustainability of services; e.g. an expanded supply of day care programmes, more homecare options or semi-independent apartments within the main residential facilities aim to allow older people to remain in their own homes as long as possible.

Moreover, Diaconia Valdese and the Tavola Valdese also provide financial assistance to families who face difficulties to meet the cost of day care programmes and residential care through its financing instrument "otto per mille".

Gianluca Barbanotti (Diaconia Valdese) next addressed one of the main issues faced by the services provided by Diaconia Valdese: the ageing workforce in the sector. The majority of carers is above 45 years old and this will create challenges in the midterm as such workers are faced with a reduced physical ability and become more resistant to change. In parallel with this, the rising average age of users, together with the increasingly diverse origin of caregivers, will also need to be tackled.

Against this framework, Diaconia Valdese is looking at the potential for automatization of caregiving and a greater role of ITCs, which can simplify and speed up work plans, medical records and management scheduling; automatized devices and avatars could be employed in surveillance, fall detection or home-based supply of medicines.





Giovanni Comba presenting the history and present of Diaconia Valdese CSD (left); the audience on the first day (right)

The first day's afternoon was devoted to two study visits to care facilities run by Diaconia Valdese: **Casa delle Diaconesse** (House of Deaconesses), a retirement home, and **Rifugio Re Carlo Alberto**, a specialised facility for elderly people affected by Alzheimer and dementia.

Casa delle Diaconesse is a resident facility hosting 29 self-sufficient and partially self-sufficient elderly people. The house is centrally-located in a green residential area close to fields, and has a big garden equipped with an open playground for children, which allows for inter-generational meeting, and a kitchen garden for outdoors activities of the residents.

After a tour around the structure, participants met with **Loredana Gaydou**, manager of the facility, and the members of the liaising Committee between the facility and the local church, for a presentation.









Casa Valdese delle Diaconesse and members during the visit.

The Casa delle Diaconesse organises several activities aimed to better integrate residents in the facility with the local community: concerts and dance sessions managed by volunteers, reading classes and short trips in the countryside. Additionally, devotions and Bible readings are optionally offered. The facility hosts a room for "Snoezelen" therapy, aiming at relaxing through multisensorial stimulation.

Upper on the hills dominating the valley, **Rifugio Re Carlo Alberto** hosts mainly elderly dementia patients who are not self-sufficient. Founded in 1898, the facility initially served people who had been refused by all other places and had no resources to afford being cared for. Today *Rifugio Re Carlo Alberto* hosts 84 people in 3 different units, depending on the stage of their condition -one of the units is also open to elderly people who have not been diagnosed with dementia but are not self-sufficient-. In addition, the facility includes a day-care centre, which aims at relieving for the daily hours families from assisting patients. In the day-care centre, patients are provided with professional cares and strategies aiming at slowing down the illness' effects. This is framed within the project '*Vengo io da te* (I come to you)", with the purpose of keeping elderly people in their home environment for as long as possible.

The Eurodiaconia delegation was welcome by **Marcello Galetti**, manager of the facility. Marcello stressed the Rifugio's willingness to be more and more integrated within the local community and fight the stigmatization of Alzheimer and dementia patients. This led to developing the project 'Ambassadors for Alzheimer', aimed to create a 'dementia-friendly community' and to foster the idea that 'life continues also after the diagnosis'. This is carried through diverse activities, such as encouraging people to volunteer with Alzheimer patients, hosting public events in the centre, engaging with schools and kindergardens, or organising exchanges with partner structures to foster 'tourism for people with dementia'. Acknowledging its activity, the Rifugio Re Carlo Alberto was awarded the "EFID (European Foundation's Initiative on Dementia) Award 2014". This award has placed the Rifugio within a network of excellence for caregiving facilities specialised in Alzheimer. The **Rifugio** is currently studying future projects, inspired by European partners in the network, on the work integration of dementia patients whoare still young enough to contribute to the society with specific tasks.

After the presentation, participants had a short visit of the facility, including two exhibitions made by local schools which had worked or a project together with **Rifugio Re Carlo Alberto** on the topic of dementia and memory.





Thursday, 6 October 2016

The morning of the second day began with a focus on the topic of Integrated care. **Dr. Viktoria Stein**, Head of the Integrated Care Academy of the International Foundation for Integrated Care (IFIC), gave a keynote speech on 'Key principles of integrating long-term care: evidence, lessons and examples from around the world'. The IFIC focuses on studies for overcoming organizational and professional boundaries between professions and institutions participating in caregiving, and simplifying integrated care practices.

Viktoria mentioned the various challenges that the present organization of health systems (community and hospital-based care), social care systems (from day care services to home-care support) and a myriad of other services (private or public) represent to patients and their families in terms of cost, availability and lack of coordination lack. Viktoria stressed how such difficulties may result in increased feelings of isolation, depression and inability to cope especially for the family carers of dementia (or Alzheimer) patients.





Two moments of Dr Viktoria Stein's keynote address on integrated care.

Looking at the "big picture", a holistic approach to health status shows the partial impact of health care on patients' well-being, which also depends critically on lifestyle, environment and endogenous aspects of human biology. Culture, education and the economy of a community also contribute, as does "self-care" and awareness of patient's care. The latter dimension includes patient education, self-care skills training, a "care plan" approach, the use of self-diagnosis tools, self-monitoring devices and home adaptation. Such large amount of variables increase the complexity of modern long-term care delivery, but the control of patients over this is crucial for the success of care processes.

Dr Stein stressed the strong overall impact of integration on health outcomes. She also mentioned that coordination is less cost-saving than cost effective. Recent studies have also confirmed that the needs of people and different population groups are diverse and one size does not fit all. Good leadership and management at different levels of the care system (and at the community) can work together towards structural integration, as cases like the Alaskan Native Community of Nuka or the Canterbury region in New Zealand have shown¹

¹ The Alaskan Native Community of Nuka has applied the principle of "consumers ownership" to health, producing a shared responsibility and commitment among citizens towards the good functioning of care systems, with excellent results in terms of enrollment in primary care, patient satisfaction, reduction of waiting lists, reduction of staff turnover and a better awareness of people's impact on their health. In New Zealand there has seen a unification of budget between home care, health system, prevention communication and community engagement, with very positive results in terms of quality improvement and integration of the care system.





The Eurodiaconia Secretariat then briefed participants on Eurodiaconia's work and advocacy strategy towards **Integrated Care** at EU level. The last reference document on the topic is the 2014 report by the European Commission and the Social Protection Committee, "Adequate social protection for LTC needs in an ageing society". Eurodiaconia reacted to the report with a meeting, co-organised with other two network organisations, on "Supporting Quality Integrated Care, policy and practices at local, regional and national levels". As a result of the input gained at the event and the experience of its members, Eurodiaconia subsequently produced a set of recommendations on Integrated Care.

Eurodiaconia is now leading a coalition of 10+ NGOs working on Long Term Care and Integrated Care aimed to raise the profile of Long Term Care in the EU agenda. Last March, a <u>document</u> with joint messages was issued calling for concrete actions by the EU regarding Long Term Care and Integrated Care. As a response to our messages, the coalition had a meeting in May with representatives of the European Commission, who stressed two key policy channels for better, quality LTC and Integrated Care; e.g. the European Semester and the upcoming European Pillar of Social Rights.

Next, **Giorgio Baret**, Director of the Coordinamento Opere Valli-Diaconia Valdese offered a presentation on homecare projects managed by Diaconia Valdese. The territory of the Waldensian Valleys, divided into 25 municipalities and with a population of 42.972 inhabitants is facing a number of strong challenges: unemployment has risen up to 30% after the crisis, population is quickly aging and young people are looking for better economic prospects elsewhere. This means that the traditional structure of the Italian family, based on inter-generational solidarity, is under pressure at the same time that the state is retreating from the rich net of services offered during the last decades.

As a response to this context, Diaconia Valdese aims at restoring community solidarity through an increased integration of services to elderly people and to the community in general, also covering youth, migrants and people with mental disabilities.

The flexibility of long term care services has become one of the flagship developments of Diaconia Valdese's action, with an increasing offer in terms of homecare, and the establishment of grants to fund the most vulnerable cases. Families are also supported through information on services, basic trainings for family members of Alzheimer patients, a thematic library on Dementia and house management.

In the afternoon, the meeting gave way to the presentation of members' flagship initiatives and ongoing projects in HALTC, with a view towards mutual learning and transferability.

First, **Petr Wija**, from the Institute for Ageing with Dignity of **Diakonie ECCB** in the Czech Republic gave a presentation on "Integrated long-term care and support services in the Czech Republic". The Institute aims to build capacity on long-term care, offering a forum for discussion and research on topics like aging, elderly care and geriatrics, community and palliative care in the Czech Republic.

The situation in the Czech Republic is challenging in terms of scarce human resources employed in nursing and caregiving. There is, however, an increasing importance given to homecare as a way to address long term care needs.

Diakonie ECCB aims at more integration between different levels of health care: health and social services, local actors and service providers, and the different levels of government. It is also making strong efforts to coordinate the transition from institutionalized to de-institutionalized care. The need to provide a continuity in care and a greater result-oriented approach responds to the demands of better performance in terms of users' satisfaction and cost efficiency. At the same time, Diakonie ECCB registers a decreased need for institutional care and shorter/less frequent need for hospitalization.





Borka Vrekić from the Ecumenical Humanitarian Organisation (EHO), next presented the working of her organisation in Serbia, with focus on its cooperation with municipalities in the provision of home care services. After the 2014 reform of the social protection system, Serbia recognizes the plurality and equal treatment of health care providers with a license to operate as such. A quarter of Serbian NGOs are providing social services as their primary activity and are generally funded by municipalities (20%), the government (18%), foreign donors (35%) and their own revenues (27%). In spite of the legal status, public "welfare social centres", local municipalities, and gerontology centers still provide most of social care services and thus public providers receive the majority of public funding. This scenario challenges the sustainability of NGOs operating in this sector. EHO is active in the sector since 2008 with the project "Home care and home help", aiming to improve the quality of life of elderly people. Homecare centers are established in the municipalities of Novi Sad, Kisac, Pivnic, Stara Pazova and Backa Petrovac, offering high quality home care assistance. In 2016, 36 nurses of the 8 active centres made 23776 home visits to 385 elderly users. Borka stressed that the financial sustainability of home care service should be boosted through increased access to state and local funds and by increasing co-funding from beneficiaries.





Borka Vrekic (EHONS) speaking on elderly care in Serbia (left) and Szilard Haris presenting a pilot training project of the Reformed Church in Slovakia.

Next, **Szilard Haris** from the **Diaconal Centre of the Reformed Christian Church in Slovakia** presented the pilot project "Home Nursing for Ukraine". The reformed Christian Church in Slovakia consists of 9 dioceses (mainly Hungarian-speaking), more than 360 congregations and about 200.000 believers, with 233 pastors. The diaconal action of the reformed Church in Slovakia is focused mainly on homecare services to elderly people and people with disabilities. This is carried out by 57 employed caregivers; the organisation also runs a training programme for people willing to become professional caregivers. The Reformed Christian Church in Slovakia has supported its Sister-Church in Ukraine since the outbreak of the war, with the collection of food and emergency items. A further project aims to build longer-term collaboration through the provision of training courses for caregivers in Ukraine. Care support is urgently needed in the country as youth is fleeing the poorest, war-stricken regions, leaving behind elderly people with care needs. The project, to be realized in 5 years, aims at providing education for volunteering caregivers in the framework of congregational diaconia, preparing caregivers for diaconal service in homecare under a quality framework supported by EU standards. Courses will be given in Slovakia, as the two congregations are set in neighbouring regions.

After members' presentations of projects, Alexander introduced Eurodiaconia's agenda on the topic of mental health. This issue is already on the service agenda of many of Eurodiaconia members but that has yet to be treated at the European level by the organisation.

As a factor of social exclusion, mental health is very connected to several other issues already dealt with by Eurodiaconia: poverty, addiction and substance abuse, long term unemployment, homelessness and in





general, people's marginalization and exclusion from a society. In light of this, participants were asked to brainstorm on the challenges faced and political actions needed to foster the inclusion of people with mental problems, and how Eurodiaconia could be most effective in this regard.







In the pictures above, Eurodiaconia members' discussions on the main issues related to mental health and policy priorities to be addressed

The outcomes of group discussions were next shared in plenary. Members all agreed that mental health issues remain a taboo in many countries, and pointed out at the diversity of profiles of people with mental health issues, by age, often marked by other social problems, as social exclusion and marginalisation, domestic violence, poverty, drug abuse but also depression. These issues are linked to economic crisis and to structural changes of European societies, where loneliness and social exclusion is becoming structural and community bonds are weaker and weaker. At the level of service providers themselves, the wellbeing of social workers and caregivers in terms of stress and motivation is also at stake and represents real challenge for service providers. Input gained from the discussion will be used to shape Eurodiaconia's work on the topic, already starting in 2017.



Eurodiaconia then addressed a few concluding words, stressing the core importance of social services and its overarching reach across members' activity. The Secretariat thanked members for their contributions and active participation throughout the two days.

Brussels, November 2016