



MEETING REPORT

Healthy Ageing and Long-Term Care Network (HALTC), hosted by the Diaconia of the Evangelical Church of the Czech Brethren (DECCB) and Slezska Diakonie.

Prague, 14-15 October 2015

From 14 to 15 October, over 15 participants from Eurodiaconia member organizations gathered at the Evangelical Church of the Czech Brethren in Prague (Czech Republic) to discuss long-term care issues faced in care practice, and also in relation to national and EU policy frameworks.

Wednesday, 14 October 2015

After a few opening words by the Eurodiaconia Secretariat, the two hosts welcomed members in attendance. **Petr Haška**, Director of the DECCB, presented the organization and its specific work on elderly care. **Romana Bělová**, Deputy Director for Social Work in Slezská Diakonie, welcomed participants and hoped for active discussions over the two days. A time for devotion led by **Štěpán Brodský**, from the DECCB, followed.



Alexander Elu, Policy and Membership Development Officer at Eurodiaconia, presented the agenda of the event and stressed the meeting's objective to bridge the work of Eurodiaconia and its members, serving members' demands for input and mutual sharing drawing from common expertise.

The meeting started with an **overview of the situation of older people in the Czech Republic**. **Olga Starostová**, from the DECCB's Institute of Ageing in Dignity, stressed the regional dimension of elderly care in the Czech Republic, noting that a majority of older people live in towns of less than 5,000 inhabitants. She then presented how the different government levels operate in the provision of care services. Olga stressed

that one of the main problems in the Czech is the disconnection between the health and social departments, which takes place at all government levels.

She then presented the results of a survey on the perceptions over elderly care in the country. According to it, a large majority of Czechs expect elderly people to be supported at their homes rather than in residential care. A majority also believes that support should be provided by families and relatives. These results are, in fact, supported by reality and the Czech Republic is the second EU country (after Poland) with the highest rate of elderly people cared for by informal carers. Seventy per cent of these are women (partners, daughters, etc.).





The fact that Czech people's expectation of being cared at home by families and relatives is met by reality should be read as a positive message. However, the same result may also be expressive of background issues such as the lack of individual responsibility –for instance, due to the sudden raise of life expectancy in the country-; or insufficient trust and information about other support options. It may also reflect poor empowerment of users.

According to Olga, high reliance on informal carers calls for a stronger institutional framework that makes this setting sustainable. With this regard, the Institute of Ageing in Dignity has developed the concept of Integrated Community Services at local level, with an important role given to coordinators in distributing information and supporting families in a better planning of services available to users. Olga also stressed efforts made to change the paradigm of elderly support, not only towards residential care but also via the community (shared living arrangements), underlined the importance of cooperation between generations and the need to increase trust in society to broaden the space of care support.

The ensuing discussion reflected on the possibility that the strong preference for home care may be due to the lack of adequate residential services. Olga agreed with this, but stressed that such preferences also had a strong generational component and the paradigm may shift in the future.

Next, a presentation from **Ivana Andrášková** and **Halina Pientoková**, from Slezska Diakonie, focussed on the **state of residential care in the Czech Republic**. Their presentation began with a general reflection on the importance of an individual adjustment period before acknowledging the fact of ageing. They also stressed that wellbeing in old age begins earlier and builds, for instance, on preventive action through adequate old-age pensions or strong links with family and relatives; such elements may ease the transition to old age.



In the Czech Republic, support to older persons is built on a 3-pillar system composed of social insurance, social support measures (housing) and social care. The presentation focused on the last of these elements, where social services aim to improve living conditions, taking into account the family, relatives, and community dimension of users.

A number of key challenges faced by elderly care in the Czech Republic today were singled out. First, there is a problem with staffing in the social care sector, as most workers have low education levels and low motivation. Workers are allowed to work in the social sector after a very short training (150 hours approx.), as this sector is often viewed as an opportunity to reintegrate persons into labour markets. These policies create tensions with the quality goals in service provision. The speakers also mentioned challenges related to the lack of users' involvement, inadequate pain and depression control among patients (too reliant on drug therapy) or the lack of male carers.

At the systemic level, Olga and Halina mentioned the great complexity of the needs' assessment for the elderly, and the difficulties in processing entitlement to care allowances. In both cases, decisions rely on the assessment carried out by medical professionals without a direct contact with seniors and the details of their daily life activity. This framework partly results in a low rate of care allowances recognized, which reduces the chance to get place in residential care, shifts the burden of care to informal carers, makes impossible to get an adequate help from in-home services and, ultimately, increases the probability of poverty among the elderly. The system is not effective in dealing, in an adequate manner, with the multifaceted dimension of poverty and social exclusion among older people. Olga and Halina also pointed at the shortage of homes for older people with mental health issues, and the lack of connectedness between social and health care at all levels.

Petr Wija then presented the **role of the DECCB's Institute for Ageing in Dignity**. The Institute, established in 2013, builds on the challenges brought by underfunded health and residential care in the Czech Republic. With help from foreign funding, the Institute's mission is focussed on the promotion of community care at the local level, aiming to develop a system of integrated support at the community level. The Institute is established as a platform for expert dialogue of various stakeholders, providing information to professionals and the



general public. It targets its advocacy efforts towards political representatives and the public administration (municipalities).



Petr then explained with some detail one of the Institute's flagship initiatives, a project of 'Support of community-based health and social services'. This is a multi-faceted project inspired by the Swedish Social Services Act, offering evidence on the financial, legal and economic conditions for the development of integrated services in communities in the Czech Republic. The analysis was presented in the Parliament and the campaign also drew on strong communication efforts. The project advocated for concrete changes, such as strengthening the competencies of the municipalities in the coordination and delivery of services, the promotion of a figure of 'coordinator of support' in the community (municipalities), and an improved coordination and

integration of services.

The Institute has also worked on a project aimed to support informal carers through counselling, help and training (Care at home -Pečuj doma-). It is also involved in a project focussing on adequate and accessible housing for older people (Am I still here at home?). The discussion focussed on the response of municipalities towards the community-based approach of the Institute's campaigns. Petr mentioned that reactions have been very positive and materialized into some financial support for community-based care. In particular, local interest has been concentrated on the role and definition of 'care coordinators'. Another point raised during the discussion referred to ways in which quality standards for community care could be defined/assessed.

Romana Bělová (Slezska Diakonie) then **presented the work with the elderly of her organization**. She mapped the menu of services provided by the organization and stressed some of the challenges encountered in each modality. Slezska Diakonie offers both community care (day care and field services) and residential care. With regard to the former, the provision of services ranges from personal assistance, respite care, distress care to day care centres. As for residential care, Slezska Diakonie supplies a home for elderly people, respite care and a special care unit.



Personal assistance services are given on a 24-hour availability, which is rare among other social service providers. Services draw on the financial support given by the municipality or regional authority and partly from users' income, which is challenging due to low income levels among older people. Making the service available is also difficult due to the dispersion of population across wide geographical areas. Romana also stressed the key role of qualified personal assistants, who need to have the skills and training adequate to perform individualized support services. Another strength in Slezska Diakonie's provision of services is their supply of distress care for people living alone. In this case, the quality of the service lies on the development of new technologies that

make the contact between users and professionals feasible.

Finally, Romana mentioned two flagship establishments developed by the organization. First, a day center for people with dementia, which is a Contact Point for the Czech Alzheimer Association. Secondly, a specialised residential care facility in Ostrava for people suffering Alzheimer's disease with a high level of dependency.

Hana Janečková next presented **two projects carried out in collaboration with the European Reminiscence Network**. Hana teaches community care and medical sociology at Charles University in Prague and has worked closely with the DECCB in the implementation of social care initiatives. The first of the projects presented involved people suffering dementia and their families in reminiscence practice ('Remembering together'). The second project dealt with the training of apprentices in reminiscence work. In



2014, 20 apprentices graduated after a set of training sessions, workshops and thematic sessions. The goal of the training was that apprentices could succeed in applying a person-centred approach that stimulates the memories of people with dementia, acknowledging that users and their families should stay at the centre of interventions. Some of the issues arising during the training had to do with the involvement of users. In particular, participants found difficulties in receiving the initiatives of people with dementia, translate their words to participants in the training; or to ensure an adequate balance of activities (speaking, video presentation, singing and hand activities).

Hana also showed some videos of a 'Watching memories matter' project, where reminiscence work was channelled through individual memory boxes in display.

Thursday, 15 October

The day started with a devotion conducted by **Romana B elov a**, after which attendants split in three **groups to discuss key topics regarding health and social services**. The groups were asked to exchange views on the main challenges faced by social services in each national context, especially, with regard to the impact of the crisis and its effects on quality in service provision. In a context of tighter public budgets in a majority of EU countries, participants were asked to give feedback on how their organizations faced the increased competition for public funds and if private sources of funding were seen as a potential, complementary alternative for this. Finally, members were asked to carry out a strategic analysis of their organizations and detect, under a SWOT framework, the strengths, weaknesses, opportunities and threats of their organizations within an increasingly competitive market for funds and service provision.

During the plenary report of discussions, participants agreed that the growing number of older people in Europe will translate into more beneficiaries for social services and an increased pressure for resources.



Some members mentioned that tighter budgets and increased competition among service providers have had an impact on **quality**. In some cases, for instance in the Czech Republic, establishments have been closed and the investment in training and qualification of staff is suffering. The effects of these will likely be felt in the mid and long-term. Users and families have had to pay a growing share of the service they are given, for instance in Italy. In this country, challenges at the national and regional level have been felt especially in the field of palliative care. In other countries, such as Sweden, the impact of the crisis has been irrelevant. It was also mentioned that higher competition and pressure on prices clashes with the core values of diaconal providers of quality social services. Participants stressed the lack of connection between the health and social sector at the administrative level, which has important effects at the policy level and in the separation of financial resources. In the Czech Republic, public authorities do not think of care from a person-centred perspective. Participants also agreed on the existence of major staff challenges. Professionals sometimes lack the motivation, training and qualifications to develop their job.

With regard to **private funding**, some members agreed that its role is likely to increase in the future and social service providers should therefore be able to identify the right funding partners. However, private funding is



usually purpose-based and should not be seen as a structural and sustainable solution to funding issues. Therefore, diversity in funding needs to be pursued. In contrast to this, public funding in Sweden represents almost 99% of social service funding and private funds do not have a significant role. Sweden is part of a national umbrella organization that seeks funds to finance social services. Some members mentioned that private money cannot and should not pay for social services running costs, but may be adequate to pay for investments in services (infrastructures, for instance). Members also pointed that PR activity and campaigns could be a possible strategy to raise awareness and thus increase the funding opportunities of social services.

Participants identified some of the **strengths** in their services. Diaconal social service providers are generally welcome with a positive public opinion that acknowledges their not-for-profit status, their Christian base (even in secular environments), experience and long history of quality social services, which often go well beyond the minimum standards required. In the Czech Republic, there has been an effective management of change and, for instance, diaconal services have anticipated inspections. Czech participants stressed the fact that their services offer a free period of care during the first 3 months, which is usually the time for an allowance to be recognized. Staff training is also an important asset, as is the good cooperation with the Alzheimer Association or an effective system of good practice-sharing and quality supervision across services. In the same vein, Italy excels in quality palliative care and has established a good network of good practice sharing at both national and international levels. Being an NGO is also perceived as a strong asset by the Swedish people, who appreciate the specificities of NGOs in a market dominated by public providers (85%) and profit-making entities (13%). Not-for-profit providers are usually more aware of the general picture, which contrasts with the fact that state-provided care in Sweden is sometimes only focused with the local context where service is provided. NFPOs are also in an advantageous position to establish partnerships with public authorities for lengthy periods of time, while profit-making providers are excluded from this.

One of the **weaknesses** identified among diaconal service providers was disproportionate reliance on public funding. Room for improvement was also acknowledged with regard to public awareness and communications (logo, web development).

Members in attendance identified as an **opportunity** the space for connection with churches and with similar organizations. Innovation in services taking place at the practice level was also seen as an opportunity to attract new funding.

Staff shortages and low training were identified as a **threat** for the future. Swedish members also mentioned the challenge represented by an adequate evaluation of person-centred care.

Eurodiaconia next presented two draft documents for review among members. The documents are updated versions of the **principles for quality diaconal social services** and the **user participation and empowerment toolkit**. The economic crisis, and related changes on the views on quality in social services by stakeholders (users, providers, contracting authorities and society at large) have made an update necessary. The papers stress that quality needs to be understood as an overarching principle concerning not only social service providers but also other stakeholders alike: users, financing authorities, the legal framework, society at large

An enabling framework for **quality** is an equally necessary core principle of social service provision and, at the same time, quality has to be mainstreamed across the whole continuum of social service provision: it starts with entitlement and accessibility, continues during the intervention process and finishes in the stages of assessment and evaluation. Alexander also stressed the importance of quality in relation to the investment approach. Social services should not be viewed as a cost for societies but rather as investments yielding both economic and social benefits, helping people to be put back on track, restoring their health, ability to work and participate fully in society. For these outcomes to spring up, services provided must be of quality.

The importance of quality also needs to be understood especially by contracting authorities in charge of financing social services. Quality elements need to be taken into consideration when assessing and awarding



contracts, otherwise the lowest price offer will always prevail. The transposition of the Public Procurement Directive into national legislation will test the willingness of governments for this.

A crucial aspect of quality social services is **user participation** and, accounting for this, Eurodiaconia's draft update of its user empowerment and participation toolkit was also presented. The main idea behind the paper is that users' ideas and experience of service provision make social services better and more effective. However, giving users a voice does not immediately result in positive outcomes for social services. For this to happen, there should be a general enabling framework where users are, first, aware of and understand their rights and, secondly, are allowed to exercise those rights by the institutional setting. In counterpart, it is necessary to acknowledge the limitations of engaging users. In particular, the voice of users should not be interpreted as unlimited licensing that overpowers practitioners and service providers' expertise. Power is not a zero-sum game and, in every case, adequate dialogue channels should be established between users, providers and practitioners to ensure that net benefits are achieved.

During the discussion, members agreed with the crucial importance of empowering users for the quality of social services. They stressed the need to underline the active nature of user experience, which eventually leads to co-production of the service. The importance of a positive attitude towards users was mentioned as an enabling factor eventually leading to better outcomes (e.g. book writing by dementia-stricken persons). Notwithstanding this, members also stressed the difficulties in implementing user participation at the practical level. They recalled the barriers to involve users suffering conditions like dementia. In these and other cases, involving families represents an added challenge.

Eurodiaconia next presented the organization's agenda on **integrated care**, which stems from previous work on the topic carried out in the last years. The 2014 European Commission and Social Protection Committee report on Long-Term Care protection needs in an ageing society was discussed in the 2014 meeting of the HALTC network. The report stressed the need to integrate care settings, with strong emphasis on the expected gains in effectiveness and cost saving.

In the wake of the report and members' input, Eurodiaconia co-organized a conference in November 2014 (with AGE Platform-Europe and EuroHealthNet) on 'Supporting quality integrated care. Policy and practice at local, regional and national level'. A Eurodiaconia document with [recommendations](#) on Integrated Care followed, which basically stressed the need to address integrated care needs from a comprehensive and holistic approach that begins with the preventive side and spans throughout the care path in an individual's life. The recommendations also called for partnership approaches as a way to help services to meet the growing complexity and comprehensiveness of users' needs.

Eurodiaconia is aiming to advocate further for IC and work together with other Brussels-based NGOs working in the topic. With this purpose, Eurodiaconia has established a coalition that will hold its first meeting on November, 4 in Brussels. Among expected outcomes is to advocate for a more strategic approach from the EU ahead of the dependency crisis or the setting a minimum standards of protection for LTC needs.

During the ensuing discussion, Romana Bělová stressed the importance of adding community, families and volunteers as key dimensions of integrated care. She underlined the need to broaden the concept of integrated care to accommodate such elements which are crucial among diaconal service service providers. In addition, she mentioned that institutional frameworks (legislative barriers, fragmentation of service provision) were often an obstacle to integration.

Eurodiaconia then presented its [brochure](#) of members' **good practices with regard to dementia-related services**. The document gathers 12 projects coming from 9 countries showing a variety of methodologies and approaches to serving dementia patients. The brochure stresses the funding aspects of projects, explores opportunities for transfer and scaling-up among members and offers some messages to guide advocacy work. First, the need for an individualized and person-centered approach. In spite of the growing number of persons affected by dementia, one-size-fits-all solutions should in every case be avoided. Dementia-related services



should also touch upon the different aspects associated with this condition, also across time. In this regard, services should adapt along the progress of the disease and start, in fact, during prevention. These goals require adequate and sustainable funding; while this is key for all social services, it is especially important for dementia-related services, where care provision spans across several years and disruptions in care provision significantly worsen conditions.

Another message to be drawn from the brochure is the need for partnerships with other stakeholders, such as IT companies, Alzheimer's associations, volunteers, etc. who may be ready to help meet the challenge of a growing and more complex demand for dementia services.

Finally, greater awareness and a more positive attitude towards dementia should also be achieved, avoiding taboos and stigmatization. Alexander stressed the brochure's role as a dynamic tool for Eurodiaconia's advocacy and practice-sharing work that needs regular update in order to adequately showcase member's practice. He also singled out some advocacy actions in progress.

Members next presented some flagship initiatives at the practice level. Louise Gehandler, from Bräcke Diakoni, presented the 'I Can' project, focused on person-centred documentation and evaluation (and showcased in Eurodiaconia's brochure on dementia-related services). This initiative stresses what persons can still do, in contrast to the standard approach of health and care professionals, who usually focus on what users' cannot do. 'I Can' identifies users' capacities through the [International Classification of Functioning, Disability and Health](#) (ICF) developed by the WHO. Users are asked about their interests, hobbies, etc., which are checked against the users' resources and abilities. Combining both, care services can be tailored individually for each user. In this way, the co-production dimension of social service provision is emphasized, as users have the opportunity to voice their needs and expectations.

Similar assessments take place in other organizations, but Bräcke Diakoni stresses the systematic approach of their activity. Louise also underlined the importance of family involvement in the assessment of capacities –in particular, when a direct dialogue with the user cannot be established-. However, family input is always checked with the user directly through additional observation.



Paola Gazzano, from Diaconia Valdese, runs a house for older persons in San Germano Chiosone, the first one established by the Valdesian Church in the late nineteenth century. The '*Asilo dei Vecchi*' hosts 99 guests and is a space for the integrated provision of services around the user.

Paola presented the variety of services offered within the *Asilo*, which range from pet therapy, memory games proposed and supervised by psychologists, a swimming pool, etc. Paola stressed the interaction between users and the community. For instance, there is regular contact with children who visit the establishment, favouring an intergenerational exchange through gardening activities, games, etc. There is also a

strong presence of volunteers (book reading) and an orchestra pays regular visits to play songs which stimulate the memories of users.

Borka Vrekić then presented the work of the Ecumenical Humanitarian Organization in Serbia and their efforts towards quality improvement of social and care services. The EHONS services benefit elderly people, sick and disabled persons who need medical or social assistance in performing daily activities, people with reduced mobility, people with chronically health problems, isolated people in poor living conditions

From a core establishment in Novi Saad, the organization has expanded to other areas, mostly rural, where the differences in needs are major in comparison with urban settings. Borka explained a major institutional change operated in the sector: a recent state license for quality services has been put in place. As of now, only 3 providers in all Serbia have obtained the license, with the EHONS being one of the successful applicants. Quality monitoring at the public level was justified as a way to promote a more diverse provision of



social services between different providers. The license may represent an important opportunity for growth for EHONS if quality is to be taken into account, as expected, in public procurement processes. This may represent a way to increase funding sources in the organization, for which public support (local subsidies) is small and reliance on users' income is minimal - as pension incomes are very low in Serbia-. Instead, most of the funding comes from partnerships with foreign donors (Swiss and German church partners). Borka mentioned the organizations' plans to up-scale (a new care centre will be opening soon).

Eurodiaconia then presented two projects where the organization is involved. The first of these is the **4Quality! Project on Personal and Household Services (PHS)**, in which Eurodiaconia is taking part through its umbrella organization Social Services Europe. PHS represent a response to the socio-demographic change brought by rising dependency ratios, social transformations and changes in household composition in Europe. They also represent an opportunity to increase the range of choice among service users, allowing dependent persons to remain at their homes while this is possible. The sector is also receiving attention and being viewed as a source of jobs, especially among persons with lower employability or currently working as undeclared workers.

The goals of the Project are essentially two. First, it aims to support a European dialogue on the quality of jobs and services in personal care and household services through a partnership approach between workers and services employers. Secondly, it aims to develop knowledge and gather data on the quality of services and jobs in in PHS, looking at factors such as working conditions, quality of services for person-centred care, professional qualifications, quality of life of service users and workers.

Romana B lov  shared her experience as a participant in the regional seminar addressing the situation of personal and household services in the Czech Republic. She mentioned that the diversity of partners involved represented a challenge when discussing the current state and future of PHS in the Czech Republic. She also added that there was some disconnection of the draft reports with national reality and expressed her hope that the final versions of the report improved this.

Eurodiaconia next presented a piece of research on the **qualifications of care and nursing assistants** in Europe. This research is being developed with financial support offered by Diakonie Deutschland and the tender issued by Eurodiaconia was awarded to Marie Woepking, researcher at the WZB Berlin Social Science Centre. The goal of the project is to have a clearer understanding of what are the qualification requirements of care professionals within the EU. It also has the related aim to address mobility-related challenges in diaconal social services.

Indeed, as the research has so far confirmed, there exist large differences in the duration of training of health and care assistants in Europe, as well as with the balance between theory and practice in training periods. Alexander stressed the complexity of mobility-related issues and the derived challenges associated to staff mobility between countries: solving staff shortages in one country may in fact be at the expense of originating a new shortage in the sending country. Alexander announced that the research will be ready by the end of the year and expects it to be a useful tool to underpin Eurodiaconia's policy messages. It may also establish a clearer understanding of qualifications in order to boost a diaconal network of care professionals, in the same vein of the diaconal platform of volunteers.

Members again gathered in small groups to discuss the **conclusions and key messages** which, in their view, needed to be taken into account. Groups coincided in their stress of the following. Members all agreed on the need to improve the status of care professionals, an aspect which needed long-term support and affected education, pay levels, training and exchange of information. With specific reference to the Czech context, members highlighted the need to promote geriatric medicine (as there are only 12 geriatric doctors in the whole country). The dignity, responsibility and motivation of workers also need to be enhanced. The groups also coincided in the need to integrate better social and health services, especially with regard to financial services.



Eurodiaconia then gave a few concluding words, thanking members for their contributions and active participation throughout the two days. He stressed the value of bringing together members operating in different national contexts but sharing diaconal values. This represents a comparative advantage of Eurodiaconia which should be further exploited through work in partnership.

Brussels, November 2015