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MEETING REPORT

Healthy Ageing and Elderly Care Network 2013

4 - 5 June 2013, Hosted by the Reformed Church in Hungary, Budapest

Participants: Laura Jones, Eurodiaconia (moderator), Barbara Mayer, Diakoniewerk Neumünster & Schweizerischer Pflegerinnenschule, Switzerland; Enikő Vetró- Bodoni, Diakonia Christian Foundation Sfantu Gheorghe, Romania; Beata Dobova, Evanjelicka Diakonia, Slovakia; Andras Beszterczey, Albert Schweitzer Reformed Nursing Home, Hungary; Kinga Ibolya Dénes, Diakonia Christian Foundation Sfantu Gheorghe, Romania; Erzsebet Bánné Kiss, Cédrus Reformed Social Institute, Hungary; Károly Czibere, Diaconal Office of HRC, Hungary; Katalin Csikó, Diaconal Office of HRC, Hungary; Laszló Dani, Diaconal Office of HRC, Hungary; Louise Gehandler, Bräcke Diakoni, Sweden; Marija Parnicki, Ecumenical Humanitarian Organization, Serbia; Sándor Imre, University of Debrecen, Hungary; Miklós Nagy, Leányfalu Elderly Home (HRC), Hungary; Dr. Agnes Egervari, Social Cluster Association, Hungary

4 June

The meeting started with a devotion led by Zoltán Tarr, the General Secretary of the Reformed Church in Hungary (RCH). Laura Jones then introduced the HAEC network, the aims of the meeting and the first part of the agenda. Participants were encouraged to introduce themselves and share concerns and expectations for the meeting.

András Beszterczey, Director of the Albert Schweitzer Home, **gave an overview of the RCH's diaconal services** and specifically **work with older people** (presentation available). Diaconal services have grown fast in recent years, the majority are in elderly care and there is a shortage of well-trained professionals.

Dr. Agnes Egervari from the Social Cluster Association presented t**he situation of care for older people in Hungary** (presentation available). She explained that older people in need of care often suffer from the ineffective interaction between the social and health care systems, being service users of both sectors. She gave an overview of the numbers of types of services provided and the eligibility criteria. She noted particularly the low level of healthy life years at birth in Hungary and the drop in government funding for high quality residential care. Strokes have a high impact on older people as awareness of stroke symptoms is low, despite the importance of quick diagnosis for better recovery.

She explained that some poor health situations are related to socio-cultural factors such as not learning self care or planning for the future and expecting the state to provide a high level of intervention, as well as families increasingly being separated by distance and a culture of only looking for external help in case of emergency. Neither dementia support nor home care are well developed and there is a need for a national action plan for dementia.

Dr. Sandor Imre presented **research on the cognitive and social health status of the oldest generation.** In one survey the most important value for this generation was family, and their continued health was explained by them as a love for work, divine providence and living a moderate life. (A summary of the research is available).

Laura Jones presented EU-level activities of relevance for the group. She gave an overview of the European Commission Staff working document: Long-term care in ageing societies – Challenges and policy options (2013) (see Eurodiaconia briefing). She explained that the European Committee for Standardisation is considering work in s**tandardisation in elderly care.** When asked if such an initiative could be useful, it

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was felt that it was a bit late as in a few countries standards have recently been adopted or are being adopted. However, it was agreed that the initiative could still be useful if linked to mutual learning between countries on the topic.

Members were asked for their feedback on the **European Year of Active Ageing and Solidarity between Generations 2012** (EY2012). Generally opinions were positive as regards the effect of raising public awareness of age-related issues, but that there was not a clear long-term impact or policy impact. In Romania they were able to run a successful gardening project with young people working for isolated older people. In Hungary a highlight was a lecture with the government on "over-care" bringing together many relevant people. The RCH organised a number of events locally and collected good practice on intergenerational solidarity. In the Czech Republic as well as in Slovakia public awareness was raised through conferences, for example. In Serbia this came about through billboards. EHO was also able to get a grant for what became a very successful project on IT literacy with older people.

Laura Jones then gave a brief overview of the Citizen's Initiative of the FEPRA organisation, a **Petition calling for long-term quality care for all.** Members would be kept informed when a formal proposal has been submitted and a decision will be made as to whether to officially support it.

András Beszterczey gave an overview of the situation of working with older people in Hungary. He explained that the care sector is one of the worst paid in Hungary and that homes are unable to pay staff as well as needed, although the situation is better in Budapest than in the countryside due to higher fees paid for care. This means that trained staff is hard to find, and that there is a brain drain, particularly to Austria. When people from the care home are hospitalised for special treatment, they often come back in worse health so the home is looking to have trained in-house medical staff to lessen the need to send people to hospital.

In terms of evaluating care needs and the financing for this the directors of homes make the evaluation based on expert opinions and on the IADL logic. Individuals usually have to complement state support substantially with their own income and up to 80% of weekly income can be taken for care costs. The state wants to further cut government support, pushing responsibility further towards the individual and the family, and even the community. Budget cuts in social care are very high and the government presents this as being forced on them by the EU. Laura Jones mentioned the work being done by Eurodiaconia on presenting moral and economic arguments against cuts to social and health care.

In the afternoon, participants visited the Albert Schweitzer home, met some of the residents and saw an example activity for persons with dementia. Following the visit, in small groups people shared the main **challenges of working with people with dementia** that they faced. Overmedication was mentioned as a problem, as well as "over-care", instead of a strengths-based or capability approach. Staff may not realize the importance of equipping or empowering an older person to be more independent or do not make the time to do this, rather carrying out the task themselves and therefore maintaining or increasing dependency. The divide between medical and social care was cited as a major challenge in ensuring effective efficient care. There is also a need to increase awareness of dementia, including through outreach programmes and to help people who may be in denial that they have it. The lack of persons with relevant qualifications and staff fluctuation was also raised.

Sometimes there is a lack of information on the possibilities offered by home care and sometimes it is not sufficiently supported financially by public authorities. Therefore it is not as accessible as it should be. A discussion on the balance between safety and freedom of persons with dementia in residential care showed this area to be a particular challenge with no easy solutions. In some cases it was felt that the law over-protected in the individual in terms of freedom, such in Sweden when a care home was obliged to buy alcohol for an alcoholic resident who consequently ended up hospitalized due to drinking too much. A topic where there were differences of opinions was on to what extent it is suitable to mix persons with dementia with others and in different stages of dementia in residential care.

Louise Gehandler from Bräcke Diakoni presented the **Alzheimer's Café** concept and their experience of it (presentation available). One of the main aims is to make dementia a topic that can be discussed, and to focus on the positive in the lives of persons with Alzheimer's. The information presented in the café setting (usually an invited expert) is aimed at the people with dementia (so mainly early stage dementia), but families and other carers are encouraged to come. It is important to find a low threshold location with easy access and to involve as many people as possible in the preparation. In their group they have a wide mix of people/stakeholders in their reference group which contributes to the planning of the meetings. They receive some church funding and the premises are offered for free for the monthly meeting by the organisation that owns the building. It is possible to run the model on a low budget through using volunteers.

Participants were asked to discuss with those around them whether this model could work in their situation or services. In Hungary it was felt that it could work in a town, where people would be less shy, but noted that as early diagnosis was currently rare there might not be as many people who could benefit from this model. For others it was felt that elements from the approach could definitely be used to develop their existing senior cafes or self-help groups.

Participants were then encouraged to **share** other **good practice** in elderly care. In Romania, Christmas tea parties are organised in cooperation between the church, diaconal centres and local government, aimed at isolated older people and their carers. Transportand a meeting place is provided by the local government. The Alzheimers association enables knowledge sharing within Romania and from aboard as well as public promotion. In the Czech Republic self-support groups for families where a person has dementia work well. A free preventive memory test is offered by Silesian Diaconia to the public. They also have a 65-hour training scheme for volunteers to accompany people at the end of life, including being trained in discussing spiritual questions. In Hungary in one oncology institute a room has been provided to host a kind of chaplaincy where people can discuss their situation with church members. The RCH hopes to mainstream this nationwide. In other countries organisations tended to rely on pastors for the spiritual care element; in some cases if there is a pastor other staff would not take responsibility for this element of care.

5 June

Louise Gehandler introduced the discussions and actions relating to **measuring "soft values" and ensuring "social content**" in elderly care services in Sweden. The aim of the government was to bring more meaning to older people in care's lives and much public money was given to projects aiming to develop social elements. However often a tailor-made approach was not taken and the same activities were provided to everyone, despite likely differences in individual preferences. Bräcke Diakoni is examining how the International Classification of Functioning, Disability and Health (*ICF*) codes could be used to measure the impact of social activities on a person's quality of life. They would like to be able to show funding authorities a collective figure for how they have improved the well-being of people receiving their services. Other countries were invited to share their approaches and also spoke of initiatives that ensure a high level of quality in care.

Dementia Care Mapping was mentioned as a tool that is sometimes used in Hungary for helping create a tailor-made care package that addresses physical and spiritual needs, but it is franchised and expensive to use (see here for more information). Imre Sandor explained that in the RCH services directors are encouraged to have qualifications in theology and a more medico-social topic. The theological degree also includes pastoral counselling. He explained that they cooperate with the European Association for Vitality and Active Ageing (eVAA). There is a method that measures a person's vitality relative to their age, which is then monitored to show if that person is ageing faster or is improving.

In Silesian Diaconia they take an individual planning approach, where the service provider staff discuss an individual's needs, including social needs, with the individual in order to develop activities and goals which can then be measured. They use different methods to measure quality of life.

Romana Bélová presented shared the discussions in Silesian Diaconia related to **working with older people with a learning disability.** Silesian Diaconia is participating in the de-institutionalisation of services for them. People with learning disabilities are living longer, age differently than those without such disabilities

and residential settings are not adapted to or equipped for older people with these disabilities. Challenges for them include that the health insurance is not willing to pay the full cost of care; ensuring staff have the relevant special training; and investing in the buildings and assistive technology. Silesian Diaconia is starting talks with local authorities about how to meet these challenges.

In Hungary it was noted that people with learning disabilities are not authorised to be admitted to elderly care homes. One way of tackling the issue is to create separate wings in a residential care home, with different communities in it. This can help a service to be financially and organizationally more viable. An additional issue is ensuring suitable care for stroke victims in residential care, who have different needs, and for who getting sufficient finance may be difficult.

The topic of the **integration of or coordination between social and health services** was then examined in more detail. It was felt this is often a problem at every level – from ministerial departments to services in care homes. In the Albert Schweitzer home, as previously mentioned they were planning on providing their own medical care which would also improve the personalization of the service and develop the relationships between care givers and service users.

Considering the challenges raised and the solutions examined, participants shared thoughts on what **recommendations** could be made and feed into the **revision of the policy paper on demographic change and social services**. In terms of what national or regional government should do, more information about dementia should be made available to the public, including the preventive measures that can be taken, such as diet and exercise; campaigns should be encouraged to this effect. This should also assist in increasing early diagnosis. It was felt that national strategies for dementia should be drawn up with all stakeholders to ensure ownership, with financing to support actions and clear lines of responsibility and control systems to ensure implementation. Legislation in the sector should take into account the specificities of small NGOs and their expertise, including the local knowledge that they can bring.

As for the EU, it must ensure austerity measures linked to its financial support do not continue to adversely affect social and health care. It should give overall principles and guidelines for care, and some considered it should lay out minimum standards. Laura noted that social NGOs were disappointed that the European Commission ended its work on quality in social services without completing some planned activities. Service providers were encouraged to be mutually supportive rather than competitive in their local environments, to learn from others, to commit to staff development and to be transparent in their work

Flexible care based on the individuals' needs and needs of society should be promoted. People must be seen as a "whole", which links to the necessity to better coordinate social and health care. The approach of Integrated Service Areas could be a tool to develop this (see for example http://www.isa-platform.eu/news.html) The case manager model also was felt to be effective in improving coordination of care and in Switzerland it works in acute hospital care. Some felt that the expense would unfortunately be seen as a barrier to implementing a national scheme, despite the potential for cost saving through efficiency gains.

The group was then asked **what the Network could do next**. Suggestions were to engage with health organisations on the issue of social and health care coordination, to hear more presentations on different methods in care (tools, activities, services, games etc) and further exchange of specific projects. Meeting in countries with diverse contexts and experiences was felt to be valuable. Information and data provision on the situations n different countries was also suggested.

Participants then shared what **follow up actions** they would take after the meeting. Many would consider how the models presented could be adapted to their contexts or elements could be taken on board, particularly in terms of support for persons with dementia and their families. One comment was that considering approaches presented would avoid "reinventing the wheel". Another was that in one organisation they would seek to strengthen the link between diaconia and the church in this area. Finally a positive evaluation of the meeting was shown by participants placing arrows on a target.

For more information, questions or comments please contact Laura Jones. (laura.jones@eurodiaconia.org)