

ADVOCACY FOR HOME CARE IN ROMANIA: THE CASE OF THE FOUNDATION FOR COMMUNITY CARE SERVICES

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The Foundation for Community Care Services (FCCS) is a non-governmental, non-political, non-profit organization which achieved juridical status in January 1996. FCCS was founded by a group of health care professionals, public health experts, and managers of medical and social services in Romania. The Foundation's mission is to contribute to the welfare of dependent people through the promotion of good quality community services that are appropriate to the needs of these persons.

How does our organization try to accomplish its purpose?

- by developing pilot projects that promote new models of community services;
- by promoting integrated work within multidisciplinary teams and within a network of institutions;
- by promoting pilot projects and their results and disseminating them to a wider population both in Bucharest and in other cities in the country (our assumption is this will make the general population and decision-makers aware of the importance of home care services and of the need to adopt solutions that have proven to be successful);
- by developing the professional and managerial skills of the professional team members through training and continuous education programs, and through expertise exchanges with home care service organizations in Romania and abroad;
- by promoting co-operation and collaboration with other NGOs and with state institutions (such as the Ministry of Health and Family, Ministry of Labor and Social Protection, district authorities and insurance houses); and,
- by drafting proposals for regulation and legislative changes in the field of social and medical services.

The Political Context in Health and Social Services

Services such as home care or hospices do not exist in Romania as public services. People that are dependent have no alternative for their care except for a few places in institutions. New emerging alternatives are being offered only by a few non-governmental organizations.

At the same time, hospitals are full of patients that, with a minimum of support services, could stay at home. It is a vicious circle — there is no network of home care services, nor are there enough beds in institutions for chronically ill patients. This requires hospitals to admit patients even with minor health problems. At the other end, when hospitals discharge patients in a community where there is a lack of services, the people end up being readmitted to the hospital because there are no home care services. As a result, hospitals are doing what social services usually do in Western countries.

Within health sector reform, after more than three to four years of preparation, in 1997 Parliament enacted the Health Insurance Law (HIL). Under the law, specific paragraphs refer to allowing for the payment of home care.

The law was implemented in January 1998 by a first wave of contracting family doctors to be providers of medical services in primary care. After four years, however, the Insurance Houses have not yet started the second wave of reforms: the contracts for ambulatory care and hospitals. These are still paid on an historical basis.

The responses of the Insurance Houses to petitions for funding home care, as foreseen by the law, have gradually passed from:

“We have no money for the hospitals and you want community care services?”

to:

“We agree that we need home care instead of expensive hospitals for chronic ... and social cases in acute hospitals BUT we have not any methodological norms for the year 2000 to be able to pay your services.”

Home care was not included in the methodological norms for the year 2000, meaning that although the law made funding possible, it was not yet included in any of the approved government budgets.

On 22 March 2000, four representatives of home care organizations that had been delegated by the International Home Care Conference in 1999 were invited to the National Insurance House with President Dr. Alexandru Ciocalteu to discuss the possible public funding of home care services.

The president expressed great appreciation for the pilot projects and gave assurances that health reform would continue and that home care services would be included in the methodological norms no later than next year. The result was that in the following year (2001), 1% of the overall budget of the National Health Insurance House was dedicated specifically to home care and rehabilitation services.

In fact, rehabilitation services were already receiving funding. For home care, the policymakers argued that the services are too new and there is no experience in designing contracts for home care. Besides that, they were not sure how to ensure good quality services within this new type of care.

It is then that we decided to develop the “Quality Standards in Home Care” project where we have worked in partnership with decision-makers from governmental organizations, and with colleagues who are providers of home care services in Romania.

Target Groups

A number of target groups have been addressed in our advocacy campaign, either separately or through joint action, in order to fulfil the Foundation’s mission.

Dependent Elderly, Potential Beneficiaries

Since home care was not part of normal service provision in the past, most elderly have responded with suspicion to the idea of home care services, even if it fills a huge need for them. They would ask questions such as: “Would you ask for my house in return for these services? Would you ask me to vote with a certain party?”

The Foundation had to start educating this group about the potential services they could benefit from and about their potential rights. As we did so, it became clearer the elderly could only be persuaded by practice, by experimenting with the benefits of home care.

Health/Social Professionals

After being trained in home care and working with dependent elderly people, health and social professionals generally understand the difference between home care and working in the health care system. They like having their independence as professionals and being able to see the difference they make to people’s lives. As a result, they become the best advocates for patient centered care/home care within their own professional groups.

Home caregivers. Prior to the advocacy campaign, home caregivers did not exist as a profession. Within our project, unemployed women were selected and trained to become home caregivers. After years of practice, some have started more advanced training in community nursing or social work. To the extent possible, the FCCS had subsidized their training.

Community nurses. Whereas nurses in the health care system mostly play the role of practice nurses with little or no intervention in the community, the community care project has boosted the role of the nurses in communities. Nurses working under the project have gradually rediscovered a meaning for their profession.

Social workers. Of special importance within the project was the idea to involve social work students in the real cases of the Foundation during their summer practical assignments. This had a high level of impact. Not only did the students like the new applied form of learning, some also opted to become part-time staff of the Foundation. They have spent on average 2-3 years working with the Foundation. Gradually they have found jobs within the system in the Ministry of Labor or with the local authorities, etc. Their understanding of the beneficiary centered culture was crucial to the further networking programs of the Foundation.

General practitioners. General practitioners have been strong allies since the beginning by promoting home care services to the patients on their lists. They easily see the benefits for their patients and are in favor of home care.

Informal Caregivers

Informal caregivers represent one of the target groups that have been addressed by the project through:

- routine day-to-day telephone conversations;
- discussions about on-the-job definitions of care giving;

- a special training program for informal caregivers in partnership with the Romanian Pensioners Association.

Mass Media Representatives

As Romania finds itself at the beginning of another era, representatives of print and other mass media outlets were (and some still are) very new to their field; most were also very young. It was difficult to have a specialized press covering areas that were just beginning to develop (i.e. health care management). We soon discovered that press representatives needed to be paid special attention if we wanted to get the attention of the general public and policymakers.

Many of the reporters “joined the club” because they liked the ideals of our mission. They found our activities were important for society and began actively promoting home care.

Representatives of Development Agencies/Bilateral Agencies of Development and Co-operation

We presented our projects to most of the development agencies in the country, even if they were not direct funders of home care services. Our aims were to:

- inform them that home care is possible and desirable in Romania, that home care represents a missing link within the overall health care system, and that any attempts to make services more efficient will be jeopardized unless some attention is devoted to this type of care;
- make them aware that their experience with home care in their countries could be of great importance for Romanian policymakers;
- get their collaboration in our endeavor to convince Romanian policymakers about the benefits of home care.

Some good examples of collaboration are:

- the Soros Foundation’s investment in the training and development of this new community-based service provider culture (see Appendix A for an article in the *Open Society News*, 1999-2000);
- the Swiss Agency for Co-operation and Development’s financial support of our service provision for three years.

Other Home Care Providers

Colleagues from other NGOs that provide home care services have always represented a point of interest. Joint conferences, job rotations, training programs, and the joint elaboration of working procedures have been like a glue that binds us together. A collaborative working relationship has been created that incorporates the threats of competitive funding, and the use of different practice models.

Now we are talking more and more about a Federation of Home Care providers. The first secured public funding would allow us the respite to advance with juridical procedures to create this federation.

Romanian Policymakers

Representatives of public organizations with decision making power have been an important target group for our advocacy campaign. Lower level people in ministries, local authorities, and insurance houses have been invited to training programs and working groups; while higher level representatives were invited to conferences and press conferences. The level of response can be directly correlated with the increased participation of their people in our activities. The level of trust was also higher as was the probability of joining one of our events.

Main Projects of the FCCS

Each of the projects implemented by FCCS had a high integration component and were intended to make sense to most of the target groups identified above.

First Pilot Home Care Service in Bucharest

This project started in early 1995 after years of previous investment in building trust with a community of elderly patients of general practitioners working in one of the clinics in Bucharest. The provision of care by the intervention team was not allowed without training.

The FCCS's standard training program for interdisciplinary teams has gradually emerged after a few training programs provided by experts in home care management from the United Kingdom and United States. It has also been enriched by the learnings from practical experience. Standard practice intervention has emerged as appropriate for different situations after practice and regular staff meetings where reflection of the previous practice and design of the practice "norm" were taking place.

These have helped in gaining people's confidence and in defining FCCS's image as an entity upon which the dependent elderly could rely. Gradually the elderly have become more and more comfortable with the benefits of home care services.

Video Production for Training and PR

Two educational documentary video productions were produced by the FCCS: one in 1996 and one in 2000. The first video documentary was produced by John Ramaekers, a professor of social work and film direction at Limburg University in the Netherlands. Putting patients first, as this documentary suggests, and explaining what home care is about has resulted in an interesting documentary that has impressed audiences wherever it has been run. It has become standard practice for FCCS to show the documentary to all new trainees during training programs, and to take it to new places when we are having a press conference or launching a new program.

Supporting the Development of a Critical Mass of Home Care Providers

The standard training programs, as well as the first practical experiences, have helped to pass on the know-how to different multidisciplinary teams throughout the country. Each of the teams has been trying to manage its own provision system within a given context.

The training programs were usually followed by a press conference which aimed to:

- introduce the idea of home care both to local journalists and to the local population;
- increase the trust of the local population toward the potential provision of home care services in their geographical location;
- increase the trust of the professionals that they themselves can do it!

In one town, Piatra Neamt, the local TV was very active in the promotion of this event. The result was that suddenly the project team was flooded by volunteers on one side, and on the other by elderly people registering to be cared for at home (in other towns, they were lacking in trust to let foreigners in their homes).

Press conferences were occasions for the important dissemination of information through the form of leaflets on home care, as well as the promotion of home care through documentary videos that were very illustrative. Practical training followed theoretical training. FCCS in Bucharest received many visits from colleagues in the country, organizing common visits to their patients and exchanging experiences.

The First Guidelines for Practice

As no other organization was involved in the provision of home care in Romania, FCCS acted as a conveyor, trying to get providers of home care together (both the ones that had received FCCS input for their initial development, and also those that had developed in different ways).

The idea was to get to a common understanding of what “good practice” means, learn from each other, and gradually refine each other’s practice according to this learning. The process used involved bringing these different stakeholders together into working groups whereby, through sharing of their practices, they could agree on the most appropriate and commonly used procedures within the provision of home care service.

The Federation of Pensioners in Romania was represented in the working group that developed the guidelines for practice. The guide was launched at the first International Conference on Home Care organized in Romania. All the participants who were involved in its elaboration were present. The conference was held in the House of the People (the Romanian Parliament is also hosted there). A press conference was organized for the occasion, where respondents included not only NGO representatives, but also members of Parliament and the Secretary of State from the Ministry of Health.

Organization of International Conferences

FCCS was the lead organizer of the first two international conferences on home care in Romania. The decision regarding the place to hold these conferences was an important one for our advocacy campaign.

When organizing the first international conference in home care in 1998, we used a collaborative approach to search for partners and to enable policymakers to take ownership over the development of our work. The Health Committee for the Chamber of Deputies, as well as the

Ministry of Health and other NGO home care providers, were our main partners in the organization of the international conference.

The Romanian Parliament is housed in the famous “House of the People,” the second largest building in the world. Conference rooms can be hired, but at a very high price unless a parliamentary committee is interested in the subject and will provide sponsorship for a specific event. FCCS succeeded not only in getting the parliamentary committee to sponsor the use of the conference room, but also to chair some of the sessions and be part of the press conference which followed.

The video documentary on home care was presented during the conference. At the end of the presentation, the beneficiary “actors” in their wheelchairs were available to answer people’s questions. The second international conference was organized in the conference room of the Bucharest Town Hall.

The Discharge Program

Once a home care team was functional and had clear working procedures, FCCS started to investigate the possibilities of networking with institutional stakeholders within the health and social care system.

For the first pilot program, the Emergency Hospital of Bucharest and the departments of Orthopedics and Neurology were chosen. Physicians and nurses from these departments received training. At first hospital managers and physicians were resistant to the idea of networking with home care services. However, they have gradually seen that their patients are well taken care of, especially dependent persons who do not have access to informal care at home, and they can free up hospital beds earlier. As a result, hospital staff are now referring patients themselves to the home care team.

The First Quality Standards Manual for Home Care Services

The same process that was used for the elaboration of the Guide for Practice Guidelines was followed. Those involved included colleagues from other NGOs, home care providers, as well as colleagues from public institutions such as the Ministry of Health, the National Insurance House, and District Health Insurance Houses from districts where active home care projects already exist. Once again beneficiaries were represented by the Federation of Pensioners in Romania. Besides using the same process, the FCCS has also produced a video documentary of the project entitled, “Public Money for Home Care.”

Results to Date

In the past five years, more than 38 training programs have been conducted in Romania; another four international training programs were held in Moldavia and Georgia. More than 850 professionals were trained in home care management during those years; of these, more than 100 are working in public organizations as decision-makers. More than 6,000 patients have been

cared for by home care organizations generated by FCCS training; sustainable partnerships have evolved between home care providers and their beneficiaries, and the pensioners association.

Four international conferences on home care were held in Romania in the past three years. FCCS also organized more than 40 press conferences with the aim of promoting home care services. The main TV channels aired more than 20 live TV shows on the topic; more than 20 hours of programming on different national and local radio channels featured debates on issues related to home care. Two video documentaries were produced: "Home Care in Romania" and "Public Money for Home Care." Two manuals were produced through the use of a participatory process that involved all potential stakeholders: the first Practice Guideline Manual in Home Care, and the first Manual of Quality Standards in Home Care.

The main outcome is that today the Ministry of Health and Family has put home care on its agenda; the National Health Insurance House is considering ways to fund home care services. The fight is not over. We are now facing an important opportunity, but also a major threat. The opportunity is to get the first public funds for home care in Romania (previous efforts have been funded through external aid). The threat is represented by the potential to hurry policymakers to make changes now that they have agreed with the idea of home care. The lack of proper management of change and the rush into this new type of service provision could undermine its main values!

Appendix A

Open Society News, Winter 1999/2000

In addition to funding direct services, the OSI program supports local groups involved in advocacy on policy issues for the benefit of the elderly, and in training and education efforts based on the principle of community-based care. Training is offered to physicians, nurses, social workers, other caregivers, and even volunteers.

"We believe that we have supported a sufficient number of pilot projects to date, representing a critical mass of good practice," said Srdjan Matic, director of OSI Public Health Programs. "A strong network of leaders in home care and community based care has emerged and their model projects are beginning to attract the interest of the local governments."

One of those leaders is Valentin Vladu, executive manager of the Foundation for Community Care Services in Bucharest, another OSI grantee. He was a family physician at the largest clinic in Bucharest when he decided to create a program specifically for the elderly.

His organization began by delivering hot meals to Alzheimer's patients at home which was met with initial suspicion by recipients. Seven years later, the Foundation for Community Care Services has overcome the skepticism and has grown into an extensive program for home care workers throughout the country. He has also garnered the support of the Romanian Government as well as international aid agencies.