

# **THE SOCIAL ENTERPRISE-PILOT MODEL OF PREVENTION AND INTERVENTION IN THE CASE OF ELDERLY PEOPLE WITH DEMENTIAS AND THEIR CARETAKERS**

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**Abstract:** The overall objective of this pilot research is to facilitate an alternative respite care in case of dementia or other disabilities for adults in question, and their caretakers, by providing specialized services at the level of Arad county and proximity; which could be disseminated as a good practice model. Implementing such a prevention and intervention model will generate a positive short, medium and long-term effect: socially excluded people or those at risk of social exclusion will be helped to integrate or reintegrate into a social context, while developing and promoting the concept of social economy through profit-generating activities and services will generate an increase in the relevance of respite services because they represent a too little developed field in Romania; respectively with an increased risk of institutionalization and / or alienation of social relations of people with dementia.

The expected results aim at the very intrinsic goal of current social assistance, which is increasingly spreading the outsourcing of social services from state to non-governmental ones (NGO); so that the use of Law no.

219/15, published in M.O. no. 561/2015 on social economy activities is a good idea to propose a model of voluntary, solidarity and private initiative with a high degree of autonomy and responsibility as the main mechanism for the creation and sustainability of new social services; generating good practice models worthy of multiplication.

**Key words:** gerontological social assistance, dementia, good practice model, social economy, social enterprise.

## **Introduction**

The intrinsic motivation to develop a model of prevention and intervention on this issue, which later serves as a pilot model of intervention, capable of being multiplied later, is in line with the objectives of different European, national and community strategies; for example, the National Strategy on the Issues and the Action Plan for the period 2016 - 2020. At present, in Romania, in the field of specialized literature on dementia and some disabilities approaches almost exclusively the medical sphere, namely the medical and psychiatric model. In this context, we need to provide services that address the individual needs of each person with a diagnosis of dementia or other disabilities, respectively to provide personalised ways to meet these needs, according to each individual's particularities.

The purpose of such an intervention is to provide a wider range of intervention, towards an expanded, personalized model, according to the individual needs of the collateral victims of these conditions: the person with a diagnosis of dementia / disability, respectively the caretaker/ s. "Institutionalization is an alternative which should only be used as a last resort. Caring for a person with dementia / disabilities can make people avoid friends, often because they feel threatened by the person with dementia / disability, not knowing how to relate to them. Thus, this makes many caregivers of people with dementia / disabilities quit most social activities.

"In Western countries, there are long-time" back-up "services, places that give the family the possibility to take a break, have weekends or even holidays, leaving the sick in these services. This kind of services can be organized for several hours a day, a few days a week or even longer, in the following places: inside the dwelling, in day / night centers, respectively in hostel type institutions or specialized hospitals (Morcan, 2012).

Younger caregivers seem to risk more than the elderly in the sense of suffering the effects of stress, just as it seems that male carers are at greater risk than women. Knowing the problems that the healthcare system has been experiencing for years, we can not help talking about overworking family doctors who do not have time to screen for dementia, and that's what other

professionals are doing in estimating customer needs. " (Tudose, 2001). The social mission of the project starts from the premise that a degenerative disease / disability is a consuming condition. It is now known to all European specialists that when caregivers (family / carers) care for people with dementia / disabilities "at least two lives are altered." Family tasks without sufficient support services become oppressive. The caretaker population is growing dramatically over the next 20 years, and the need to care for loved ones will become a norm. Often caregivers are aging people, and they continue to provide permanent care, hygiene (bathing, clothing) to people with dementia / disabilities at their home, rather than resorting to alternative institutions. În câteva cazuri, aceste responsabilități sunt echivalente cu trei slujbe, full time. Most caregivers provide care from one to four years, including 60% of full-time care for at least three years. The effect on caregivers is predictable: physical and emotional health being affected. Family caregivers suffer more stress-related illnesses, such as: decreasing immunity, more than the general population. These factors are exacerbated by the fact that 36% of carers are at least 65 years old. 12% of caregivers of Alzheimer's report suffering from mental illness, a direct consequence of care. Unfortunately, caretakers who have these tasks for many years also lose or damage their personality, identity and will. Statistics argue these general statements saying that they are stories rather than realities (Morcan 2012). According to Government Ordinance no. 86/2004, specialized social assistance and social care services are carried out within multidisciplinary teams. In the absence of the development of an integrated service system at local and national level, many of these initiatives were, either interrupted or continued, have proven useful and still survive, but isolated initiatives remain, proving interventions with a relatively low impact. Consequently, we appreciate that we are confronted with a reality which, in a synthetic way, is as follows: in public health policy in Romania, dementia / disability in many of its forms is not declared a priority; there are major delays in the adoption of official documents on sector-specific legislation; the institutional framework for the provision of health care and care services is at an early stage; social support systems for the family / carers of people with dementia are not sufficient and are inadequate; financial support is not an element taken into account and individualized in the national and / or local budget allocation; the lack of stimulation of clinical and fundamental research, as well as a sufficient amount of epidemiological data, constitute a constraint in the development of sequential policies specific to neurodegenerative diseases, respectively dementia. Given that the created packages will provide diversified services, anchored to needs not covered by other existing services; the type of day services, the proposed activities and those offered in the accommodation type packages - as a "respite" solution, we believe that the present project will

contribute directly to the achievement of at least 3 objectives within this strategic plan, namely Europe 2020, proposed in the case of dementia and reflected for other disabilities: encouraging active aging and reducing public expenditures on old-age assistance, the institutional framework for provision of services, social, medical and care services still in an early stage; developing and implementing social support schemes for the family / caregivers of people with dementia still not enough and inadequate; shaping a framework to stimulate clinical and fundamental research as well as a sufficient amount of epidemiological data that can contribute to the development of sequential policies specific to neurodegenerative diseases such as dementia and Alzheimer's disease. Secondary theme of the proposed model is social innovation as it proposes new solutions and models of intervention, by creating specific intervention models and good practice, as well as by increasing the quality of life for served people. Thus, the results generated by the project will aim to increase the quality of life, respectively to create models of good practice that could be multiplied in other communities and in society, able to produce the structural social change at the cultural, normative or regulatory level of the society. In other words, non-discrimination, because we are addressing vulnerable groups at increased risk of marginalization and social exclusion, due to the acute lack of specialized services for these target groups. As the horizontal theme, the purpose of this innovation is not the profit, but the ability to generate personalized services in response to needs, in the idea of being disseminated through organizations, individuals or enterprises whose main purpose is the social.

### **Methodology**

One of the tools used is the SWOT analysis of the proposed model as well as the case study and the structured interview. Strengths (S) - Creating self-sustaining services by setting up social enterprises that will generate new and self-sustaining respite services for the beneficiaries and their owners, which give their owners a period of time to relieve themselves of their daily responsibilities of caring for people with dementia and / or other disabilities; Weaknesses (W) - high price of services - lack of sufficient information regarding the service; Opportunities (O) - the current context that promotes institutionalization by focusing on remaining skills rather than on disability; Threats (T) - The mentality about the social economy, namely the existing competition on the local market, is represented by the elderly centers and old-age care homes, which can still be perceived as an alternative to care services;

*Anamnesis on the phenomenon. Case study, Arad County, Timis, Hunedoara and Caras.* The social issue, in the case of people with dementia / disabilities and their caretakers, is little to be dealt with in the practice of

assistance. In all European countries and beyond, there are a number of services available directly to this social category, including: community hospitals, elderly centers, dementia support groups and caregivers, educational programs, home food delivery services, helper-based homes - group living, case management organizations, information services, etc. The intervention of social assistance in the case of dementia / disability must also necessarily involve its family as an increase in the awareness of families about the disease will induce them to be aware of the measures they might take to protect themselves and the sick person; I here refer to social, legal, care. On the other hand, this early intervention could help to improve the quality of family life by properly addressing behavioral disorders. We consider it very important to orientate all efforts to improve the range of services for people diagnosed. Assessing the condition of caretakers during illness has not been a concern for researchers, although it should be a prerequisite for providing adequate intervention and support services. For all of this, developing good practice models and, implicitly, government programs is intended to be a basic condition. Improving the quality of life of a person with dementia / disability, whether in the community or in a home decor, should become a priority for social research; and we propose the model we offer to create the context for this. I think it is time to make our citizens accountable, to raise our awareness of the sick and ill. The identification of psychosocial influences is a very important process that can have a positive or negative effect depending on how they intervene at the "micro, mezzo, or macro level of practice." (Coulshed, 1993).

We must have the courage to admit that dementia / disability is no longer a problem of the individual and his / her family, we are talking about a national problem due to socio-economic implications, and at the micro level it presents itself as a problem of the community that it is part of . Within this framework, the social worker needs a series of ethical and moral qualities, skills and aptitudes to help them meet the needs of this category of beneficiaries, representing their rights, interests, but not forgetting that they represent an individuality different from other categories of people but having something to say, and should be supported in this direction.

### **Research hypotese**

1.1 Analysis of the current situation of the studied areas, through a descriptive and correlative design, starting from the need for specialized respite centers for people with Alzheimer's dementia and their caretakers. In order to describe the current situation of Alzheimer's dementia care centers in the studied areas (Arad, Timis, Caras and Hunedoara counties), the statistical processing of structured interviews dedicated to specialists working in the care centers for

people with Alzheimer's dementia and those related to the caretakers / family, those who have in their family or care people with Alzheimer's dementia.

1.2 Based on the premise that Alzheimer's dementia affects at least two categories of people, the patient and the caretakers, a descriptive design will identify the current situation of the Alzheimer's dementia / families in the studied area.

### **The Research Objective**

*Creating a social enterprise model with services / packages.* Through this model, we intend to maintain and develop the activity of a social enterprise, both in terms of the social mission and the business (economic) model of the enterprise. In this sense, we thought more packages of services addressed to both beneficiaries and the caretakers: The main services offered are grouped on packages (which can also be adapted according to requests) as follows:

1. *Package „DAY”* - 70 RON / day 8:30 - 17:30 - Surveillance - Food - breakfast, lunch and snack in the catering system - Daily activities (according to the plan of services and activities): Educational programs, Occupational therapies, Recovery activities, Activities to improve and maintain physical condition, psycho-social therapies - on demand and surcharge on certain days of the week: Massage therapy; Maintenance services and personal hygiene (haircut, shaving, manicure, pedicure)

2. *Package „Weekend”* - 250 RON (Saturday from 8:30 until Sunday at 17:30) - Surveillance and care 24/24 - Food - breakfast, lunch, snack and dinner in catering system - Daily activities according to the plan of services and activities): Educational programs, Occupational therapies, Recovery activities, Activities for improvement and maintenance of physical condition, Psychosocial therapies - Daily hygiene.

3. *Package „Extended weekend”* - fare 300 RON (Friday from 8:30 Sunday at 17:30) - Surveillance and care 24/24 - Food - breakfast, lunch, snack and dinner in catering system - Daily activities (according to the plan of services and activities): Educational programs, Occupational therapies, recovery, Physical improvement and maintenance, Psycho-social therapies - Daily hygiene - On-demand counseling on certain Fridays: Massage therapy; Maintenance services and personal hygiene (haircut, shaving, manicure, pedicure)

4. *„Weekly Day Package”* - 60 ron / day Monday to Sunday from 8:30 to 17:30 (420 RON) - Surveillance - Food - breakfast, lunch and snack in catering system - Daily activities according to the plan of services and activities): Educational programs, Occupational therapies, Recovery activities, Activities for improvement and maintenance of physical condition, Psycho-social therapies - On request, certain days of the week: Massage therapy;

Maintenance and personal hygiene services (haircut, shaving, manicure, pedicure)

5. „*Weekly accommodation*” package - 600 RON (Monday 08:30 until Sunday at 17:30) - 24/24 supervision - breakfast, lunch and dinner in catering system - Daily activities (according to the plan of services and activities): Educational programs, Occupational therapies, Recovery activities, Physical improvement and rehabilitation activities, Psycho-social therapies - Daily hygiene - On request, for a certain fee, on certain days of the week: Massage therapy; Maintenance services and personal hygiene (haircut, shaving, manicure, pedicure)

6. *Package „2 Weeks of accommodation”* - 1000 RON (Monday 08:30 until Sunday 2 at 17:30) - Surveillance and care 24/24 - Food - breakfast, lunch, snack and dinner in catering system - Activities (according to the plan of services and activities): Educational programs, Occupational therapies, Recovery activities, Activities to improve and maintain physical condition, Psycho-social therapies - Daily hygiene - On request, surcharge, in some days of the week: Massage therapy; Maintenance services and personal hygiene (haircut, shaving, manicure, pedicure).

7. *Transport package*: 30 RON - round trip to municipalities + 10 RON in neighboring areas.

8. „*Training, Counseling and Support for Residents Package*” - Tariff 50 RON / hour - Individual and group counseling; (which may include therapy) - Psychological counseling and social assistance; - Beneficiary rights counseling; - Supportive therapy and counseling in order to relieve them of excessive responsibility, in order to reduce the stress associated with care and to facilitate the continuation of the social role; - Developing skills for carers / for cognitive stimulation of the person with dementia / disability through games and logical exercises / preventing their marginalization and stigmatization / improving the level of knowledge about illness and care;

9. „*Assistance to Obtain Beneficiary Rights Package*” - 500 RON Fee / file - Realization of the documentation for rights and re-evaluation of people with dementia or other disabilities; The tariffs for the services provided by the center / respite centers will be negotiable and the packages can be adapted to the needs of the clients. These packages and services can be multiplied later in other centers and organizations, and experience gained through „project” and depending on the results will be open to other local and / or regional centers. It should be mentioned that, on the social economy model, these costs can generate the self-sustainability of staff services, administrative issues, etc. For a residential center with a day-care feature, type of holiday with all the specialists paid by the project / capacity 15 in accommodation / residential, respectively 20 per day-leisure activities.

Considering the purpose of the project to minimize the risk of social exclusion, the development and promotion of the concept of social economy through profit-generating activities and services; as well as increasing the relevance of respiration services, the presented model aims at achieving the objective of facilitating a respite alternative in the case of dementia or other disabilities for the adult adults and by providing specialized services at the level of the 4 counties. Strengthening the capacity of social economy enterprises to operate in a self-sustainable way and investment priority as well as promoting social entrepreneurship.

### **Principles**

1. *Gender equality* - by carrying out the activities, they will have as a prerequisite the provision of an environment favorable to gender equality and gender equality. The European Union and the Council of Europe promote fundamental rights: non-discrimination and equal opportunities for all. The project will respect the principle of equality by combating the stereotypes attributed to different people, regardless of ethnicity, disability, age, religion or sexual orientation, as well as the need to change attitudes and behaviors that affect in some way human dignity. The actions taken in this directive will aim to create new models that do not reflect the stereotypes mentioned above at the society level as well as the full integration of people with dementia or other disabilities into everyday life.

2. *Non-discrimination* By the nature of the activity, the care of people with dementia and disabilities, the staff working with them will be excellently tolerant, psychosocially motivated in offering equal treatment to all those in need. But to ensure that everyone benefits from the same protection against discrimination through this model of intervention, we aim to generate changes in mentality and behavior in the community and society. Thus, in our work, we will be very careful about the principle of non-discrimination on grounds of age, nationality, race, color, ethnicity, religion, political option, social origin, disability, situation or family responsibility. This model could be part of the reform that is being sought in the case of people with dementia or disabilities, in order to break down the high walls in the absence of adequate legislation, specialized services, and unanimously agreed constitutional rights and principles.

3. *Accessibility for people with disabilities* The target group will be especially made up by people with various dementia and disabilities, who will need primary care, care services, and psychosocial assistance. Thus, the specialists will be trained to work with such people and will be able to use their skills acquired during the training session. By accessibility, we mean helping them to fulfill their roles and responsibilities, and to have the same possibilities



of individual choice and the same degree of control over their lives as those who do not suffer from any disability. Actions undertaken in this field should take into account the need to ensure access, accessibility and social inclusion, as well as for others.

*4. Demographic Change* According to research in the field, it is clear that in the coming decades, the proportion of elderly people will grow rapidly in all EU countries, while the proportion of the working-age population will drop significantly. Although increasing life expectancy is an important achievement, the aging of the population is a major challenge for the economy and for European social protection systems. (Rotman and cal., 1995). Thus, the specific problem of gerontological social care can be represented by adults with dementia and / or disabilities; whose increasing number is directly proportional to the demographic changes that occur in the elderly; the lack of social services that is meant for them.

### **Participants**

The participants in the study included 120 demented and 80 homeless people; respectively 10 existing institutions as providers of social services in the counties of Arad, Timis, Hunedoara and Caras.

### **Instruments**

In order to create successful models, we propose some attributes and roles to create a pilot model of breather prevention and intervention for:

The CENTRAL COORDINATOR aims at: providing and organizing the respite center in order to start the activity, daily coordination of the activities of the center, selection of the beneficiaries with dementia other disabilities in the respite center as a daily activity / and of those for package accommodation; on the basis of the primary assessment on arrival, and the conclusion of a contract for the provision of social services, the purchase of food in the catering system, the transportation of the employees and beneficiaries for various activities in the community, planning and solving of the requests from the owners regarding the accommodation and reception of the beneficiaries in the center.

The SOCIAL ASSISTANCE activity aims at: social and educational intervention, life skills and social behavior, self-management, manual work, gardening, expression therapy; occupational therapies and speech disorder therapy; Activities to maintain the remaining skills as long as possible; Art and craft workshops; socialization activities; Support in order to obtain rights provided by law, counseling and therapy.

The roles of the PSYCHOLOGIST aim at: Psychological and Psychotherapy Activities: psychotherapy / training and development of independent life skills "EDUCATIONAL PROGRAM SPECIFIC FOR HOME"

education and information programs to prepare the family and / or social reintegration/ integration; psychosocial intervention in order to significantly improve emotional disorders - depression, apathy, restlessness;

The role of the CARETAKERS: Surveillance, guidance, providing food, maintenance and personal hygiene; Activities to improve and maintain physical fitness of moderate intensity. If the budget would allow it, the following would be necessary LOGOPED, PSIHO-PEDAGOG, MEDICAL ASSISTANT, PRIMARY MEDIC AND PSYCHIATRIST.

### **Procedure**

Following the realization of proposals for models of prevention and intervention on social economy structures, we will send to all those interested the model project "obtained" as a result of the study, with the aim of increasing the financial sustainability to generate respiration services in order to increase the quality of life for people with dementia; by preventing the increased risk of institutionalization and / or alienating social relationships to the next of kin of the people with dementia.

### **Results**

The principles that should guide the intervention of the social assistance specialist in this sphere should focus on several areas of intervention; which involves the development of roles and tasks such as: *Abolition of the label* (acting as a mediator, advocacy role) *Manager* - co-ordinates and facilitates access to important social and medical services for the therapeutic process and for good social reintegration; *Educational role* - in the relationship between the patient / beneficiary and his / her family; forming support groups, organizing recreational activities, creative workshops, etc. *Family orientation* - the dimension of family support is very important, as even economically, it is less expensive than if the state takes full responsibility of these attributions; *Representing and promoting* the rights of people with dementia; *Intervention focused on the environment* - accompanying the client with dementia in the relationship with the state, with the civil society; *It models*: the relation of the client with the social environment (state / non-governmental); *Determine the person's autonomy* - oriented on the dimension of social reinsertion; *Representation (advocacy)* - social, legal, family related, community; *It develops, proposes and implements* effective policies for people with dementia; *Identifies, accesses and attracts funding* - for this segment of activity too; *Facilitator* - to develop independent life skills; *"Social treatment"* (AASW, 1931). Providing free legal advice - well aware of the rights and facilities offered to this category of people. *The counselor* (on the management of the

disease) is very different, in this report the social assistant plays several roles including the confident, counselor, support, the relationship being able, under certain conditions, to exceed the "boundaries" of a strictly professional relationship - towards an interpersonal relation; so the social worker will be invested with more confidence; which will lead to safer successes. An integrated intervention is needed (Karen et al., 2001).

### **Discussions**

"Because almost all literature about psychiatric patients is written from the point of view of the psychiatrist - and the psychiatrist from the social point of view is on the opposite side of the patients." (Erving, 2004).

The main *objective of social care in the gerontology of demented people* should be *to rehabilitate the individual in a social and family context*, thus enabling him to live as independent as possible in relation to his or her capacities, and not to encourage institutional dependence (of recurrence/ relapse type ).

We must not forget that empathizing with the elderly, we even empathize with our individual future" (Neamtu, 2003). In a famous article on the International Year of Elderly Persons (1999), Galambos and Rosen highlighted five basic principles for the elderly: independence, participation, care, self-esteem (fulfillment), dignity"(Stanciu, 2008).

### **Conclusions**

Besides the social worker's roles in working with demented people or their next of kin, some working principles should be outlined, of which the most relevant would be: community responsibility, community co-participation, ensuring continuity of care services, emphasis on rehabilitation, a specialization of care services, the family seen as the main pillar both in the care and rehabilitation process, the desensitization of the population and the emphasis on rehabilitation. It is a discussion of an era of "social psychiatry" in which the patient is viewed as a whole as a "bio-psycho-social" figure (Suciu, Ardelean, 2007).

A profile of the psychiatric social assistant, which also includes a lot of the social attributions of the psychiatrist, should be increasingly outlined, providing social assistance at the highest level, both at hospital and community level (sheltered housing), but especially ambulatory - as intervention and prevention.

The social worker must intervene in this process of rehabilitation, recovery as a binder between services and individuals, ensuring throughout this period that the patient is given the opportunity to work, to establish relations with the neighborhood, to take action and make decisions on its own, and last

but not least, to benefit from a secure family climate that can provide support on the one hand and, on the other hand, give him the confidence to act on his own.

Since the early 1990s, the tools used for the early evaluation and diagnosis of Alzheimer's dementia in Romania were made only in the late stages of the disease; Snyder (1999) explicitly stresses the urgent need to engage in active awareness policies of the general population on Alzheimer's dementia, namely the development of programs such as information support groups, information campaigns, lobbying and advocacy for community support and unprejudiced acceptance of people diagnosed with Alzheimer's dementia. It is known that in other societies social support is a predictor of quality of life in people diagnosed with Alzheimer's dementia.

At Community level, for the success of the intervention in the family of the person diagnosed with Alzheimer's dementia, teamwork is required. For this, it is necessary to set clear objectives, which can be perceived by all team members; otherwise the results can be devastating (Karen et al., 2001). There is a need for a structure of the team and members to be connected to objectives, in this sense the main characteristic would be unity and efforts oriented in the same direction. It is the commitment of the whole "team / community". A change at a social macro level requires changes in values, beliefs or behaviors. It is necessary to demolish barriers such as preconceptions ... and to develop social militarism in the sense of accepting this new disease, but with such profound repercussions. For all this, a long-lasting engagement and effort is required!

Indeed, a specific problem raised by Alzheimer's dementia, especially in Romania, is the late diagnosis. According to statistics, in Romania only 10% of Alzheimer's dementia sufferers are diagnosed and only 10% are treated appropriately. From the observations made and the study of the files of the institutionalized people with dementia, there is either a sub-diagnosis of the person or an over-diagnosis (Morcan, Tranca, 2012).

Unfortunately, at the level of Arad, Caras and Hunedoara counties, the existing community centers do not carry out activities in the community but in isolation, such as rare trips or hiking, but do not intend to meet the community through awareness raising and information campaigns of this disease; while Timis has the only two units of specialized dementia. Despite the importance of the family in the care of these patients, there is very little study describing the way and the place where the person with Alzheimer's disease spends time, as well as the practical, economic and psychological impact on the caregiver.

Another goal of this research is to create this model anchored to the strategic plan for implementing the European Innovation Partnership on active aging and in good health conditions.

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