

## QUESTIONNAIRE: Slovenia

### 1. Assessment of behavioural disorders

#### 1.1 Please specify the different kinds of behavioural disorders which in your opinion need to be assessed:

Dementia is not only a serious medical condition. Its consequences also have a deep impact on a person's social functioning which presents a challenge for the new understanding of behavioural disorders. Due to characteristics of dementia, the persons concerned are not able to maintain their existing social contacts, the environment tends to exclude them, with the consequence that their capacities gradually deteriorate even more. Also the relatives of persons with dementia become socially excluded in a way, for they invest all their energy and time to the person with dementia and increasingly neglect their usual social activities; instead they spend most of their time with person with dementia and in consequence grow increasingly lonely, too. Social exclusion of persons with dementia and their relatives is certainly one perspective of understanding of their behaviour.

“Behavioural disorders” follow the medical model of treatment since its focus is only on dementia as an illness which leads to a complete deterioration of the persons functioning. We understand dementia as a phenomenon characterised by the negative attitude of the society, changed social behaviour of persons and also by inadequate physical environment of their living. Therefore we are following Kitwood's (2006)<sup>1</sup> concept of understanding dementia. Kitwood has placed the person with dementia in the centre of interest. He has widened the classical medical understanding of dementia as a disease causing fatal cognitive changes by inclusion of the (frequently negative) influence of the social networks on the development of dementia. The author differentiates between the influence of informal (relatives, friends) and formal (various professionals who deal with persons with dementia) social networks. Kitwood is further convinced that we can learn a lot from people with dementia who experience their emotions very intensively and without constraints.

#### 1.2 Describe the most appropriate approach for this assessment:

Dementia is a serious experience for everybody involved in the interpersonal relationships: the persons with dementia, their relatives, friends, neighbours and also the professionals. The consequences caused by dementia often bring about constraints in understanding each other. Our approach is based on the needs of people with dementia and their relatives. The specific nature of our approach lies in a holistic understanding of the individual and his/her needs and in the assertion of the user as a partner in the helping process in order to foreground his right to choose different kinds of help. By identifying the needs of older people, people with dementia, we can contribute to the development of various programmes and services and to their mutual connection. Therefore we need to improve interactions between older people and their family or the wider social environment. Families with a family member who has dementia have to reorganise family life in a way that will be acceptable for all family members by giving them appropriate information to assist them in the reorganisation of life and by training them for living with people with dementia.

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<sup>1</sup> Kitwood, T. (2006), *Dementia reconsidered*. Berkshire, New York: Open University Press, McGraw-Hill.

### 1.3 Describe the most used measurement / assessment tools for these symptoms:

Our approach is based on holistic understanding of the individual and his/her needs and in the assertion of the user as a partner in the helping process. That conceptualisation needs certain principles to be observed and very useful are the concepts of social work with the older people Burack-Weiss, Brennan (1991: 5-14)<sup>2</sup> described:

- **Seeking Strengths:** The behaviour and actions of social workers should go one step further from mere identification of problems. They should provide help and support for older people to draw strength from their rich life experience in order to overcome their present problems. At the forefront should always be the older person and his/her abilities and capacities, and not mere problems, as there are in many specialised programmes and services for solving their problems.
- **Promoting Maximum Functioning:** Older people are threatened by various types of loss which occur both at the level of individual's functioning and at the level of his/her social role. Social workers are therefore not focused only on individual losses which the older people often face, but also take into account the entire life context in which these losses appear.
- **Promoting the Non Restrictive Environment:** Individuals have the right to live independently in the kind of environment and in the manner that will not endanger their lives and the lives of others. The transition from a functionally inappropriate living environment to a more suitable one requires a gradual approach and maximum respect for individual's desires, needs and requirements.
- **Promoting Ethical Practice:** Ethics reminds us not to neglect two basic ethical principles during work with the older people – respect for and preservation of their dignity. Only in this way can social workers establish a working relationship with them, which constitutes the basis for our professional work, and not overlook the rights of older people.
- **Respecting Cultural Differences:** One of the characteristics of heterogeneity in the older population are ethnical, cultural and national differences between older people. Ethnicity affects the choice of assistance and attitude to living in an institution, as well as acceptance of diseases and relationships within the family, and at the same time also affects the relationship between the person and the social worker.
- **Working within a Systems Perspective:** Another specific feature of social work is that social workers interact with individuals and their environments. This is especially relevant during social work with the older people, as older people are often dependent on the help they receive from their social environment, either on the informal level (help from their families, relatives, neighbours, friends and acquaintances) or on the formal level (help of professionals from various organisations and institutions).
- **Setting Appropriate Goals:** To achieve appropriate goals, social workers and users need to set them together. They should be based on the actual situation and the individual's circumstances and should at the same time motivate the user for optimal activity to achieve the set goals.

<sup>2</sup> A. Burack-Weiss, F. C. Brennan (1991), *Social Work with the Elderly*. New York: The Haworth Press.

## 2. Types of home care provision provided by professional carers

### 2.1 Please describe different approaches to supporting and caring for people with dementia who live at home related to behavioural disorders:

In Slovenia, there is a lack of community programmes for persons with dementia, as well as of informal, and professionally trained formal caregivers which could support them to be able to live in the community for as long as possible. The institutional care for older people is the most widespread form of care for the aged. In last 10 years, some new forms of the care for the older people that replace institutional care are being developed: for example day centres for older people, home help for the older people. It is interesting that those services are in many cases provided by the older people's homes. Home help is still not developed enough. In 2008, home care services were provided in more than 95 % of Slovenian municipalities to almost 6.000 people older than 65. In the same period the network of cross-generation and self-help groups and other programmes expanded 22 day care centres, 6 regional remote assistance centres in the country, while sheltered housing was constructed at 9 locations considerably. These groups provide for lesser social exclusion of the older people in their living environment. The Ministry of Labour, Family and Social Affairs co-financed 5 providers with the total capacity of over 1.319 groups for the older people (Ministry of Labour, Family and Social Affairs 2006: 48)<sup>3</sup>.

The majority of people with dementia live in their home environment where they have to cope with diverse problems. The relatives who are the sole caregivers for persons with dementia who still live in community tire out at providing direct care for them. They are unable to find additional sources of either formal or informal help. What they would need are diverse forms of help, ranging from provision of information and training about adequate care of the older person with dementia to an extensive personal help and support. At present, only few forms of formal help within the community environment are being offered, therefore the burden of care is mainly on the family members and other informal caregivers, in most cases the relatives or the neighbours. Within the family, it is mostly women, who take over the care for their aged parents. Some of them may still be employed, others already retired and due to their own medical condition and age unable to provide adequate care for the sick relative. They have virtually no information on the care of persons with dementia and are torn between the responsibility of caring for their parents and their own families. The difficulties they most frequently quote include work overload, their own health problems, financial problems, poor understanding of, and insufficient knowledge about dementia.

### 2.2 Describe the appropriate non-drug treatment or measures used:

We are developing only non-drug treatment. See 1.1. – 2.1.

<sup>3</sup> Ministry of Labour, Family and Social Affairs (2006), National Report on Strategies for Social Care and Social Inclusion 2006 - 2008. Ljubljana: Ministry of Labour, Family and Social Affairs.

### 2.3 In what circumstances is residential / institutional (including hospital) care required?

It is estimated that about 5% of people older than 65 years in Slovenia has dementia, but the share of people with dementia older than 80 years is 20 % (Mali, Milošević Arnold 2007)<sup>4</sup>. In Slovenia, the institutional care for older people is the most widespread form of care for the aged. According to Kaučič (2006)<sup>5</sup>, the entire share of residents homes for the older people with dementia in 2002 was 20, 8%, but the empirical data gathered in the research in years 2003 - 2004 (Work with Persons with Dementia in Homes for the Elderly. A Model of Treatment, Faculty of Social Work) show that the share of residents with dementia is growing, for instance in some homes for the older people the share of people who have signs of dementia is even 60% (Flaker et al., 2004)<sup>6</sup>.

In Slovene homes for the older people, three different models for the treatment of the residents with dementia are prevailing: the integrated, the segregated and the semi - segregated one. Within the integrated model, the residents with dementia live together with other residents thus fostering mutual understanding and acceptance which has a positive impact upon the treatment of persons with dementia. Some homes apply the segregated model of the care of persons with dementia; they accommodate them in separate, specialised and sheltered wards. Some homes decided for a kind of a mixed, partly segregated form of work, for instance setting up special groups for persons with dementia. On the grounds of the data collected in the above mentioned research, we designed a social model of care for persons with dementia which is based on an individual approach and equal cooperation of health and social care services. It is an integrative model of treatment within specialised programmes adapted for the residents in different stages of dementia. Hereby, an individual team formed as a project group for each individual resident plays an important role. Their members are all the staff who directly works with the resident with dementia within the home, but also anyone concerned with their wellbeing, including the staff from other institutions, volunteers, and advocates. The main task of such an individual team would be to provide individualised services for each resident based on his individual plan of services instead of a package of services available to all (Flaker et al., 2004: 99). Individual services would allow choices whereby the team would see to their implementation since the resident himself does not have the power for that. The essence of the social model of the treatment of people with dementia in homes for the older people is represented by: the individual approach, along with participation and care for good interpersonal relationships within residents' informal (relatives, friends) and formal social network (staff).

<sup>4</sup> Mali, J. (ur.), Milošević Arnold, V. (eds.) (2007), *Demenca – izziv za socialno delo*. [Dementia – A Challenge for Social Work]. Ljubljana: Fakulteta za socialno delo [Faculty of Social Work].

<sup>5</sup> Kaučič, Z. (2006), Review in Institutional Care for the Elderly and Adults with Special Needs with the Indicators of Data Processing from the Performers' Reports for 2005 [Pregled področja institucionalnega varstva starejših in odraslih s posebnimi potrebami, s kazalci obdelave podatkov iz poročil izvajalcev za leto 2005]. Ljubljana: Skupnost socialnih zavodov [Association of Social Institutions Slovenia].

<sup>6</sup> Flaker, V., Kresal, B., Mali, J., Milošević Arnold, V., Rihter, L., Velikonja, I. (2004), *Delo z demenčnimi osebami - priprava modela obravnave oseb z demenco: končno raziskovalno poročilo* [Work with Persons with Dementia – the Preparation of the Model of the Treatment of Persons with Dementia: final research report]. Ljubljana: Fakulteta za Socialno delo [Faculty of Social Work].

### 3. Training programmes / information

#### 3.1 Which kind of information, training and education do exist for people with dementia and their carers?

The relatives who provide care for persons with dementia are often overburdened with work and consequently lack the time for them. Gradually they abandon the activities which could provide relief for them; some of them cannot even afford to go to a doctor when they need one. At the same time persons with dementia are distressed too because they are dependent on other people, mainly the relatives. Due to insufficient knowledge about the disease and lack of information on how to treat a person with dementia, the relatives often feel insecure, worried and even scared. The available professional help is generally good, but still insufficient to present a real relief for the relatives.

The relatives who are the sole caregivers for persons with dementia tire out at providing direct care for them. They are unable to find additional sources of either formal or informal help; What they would need are diverse forms of help, ranging from provision of information and training about adequate care of the elderly person with dementia to an extensive personal help and support. At present only few forms of formal help within the community environment are being offered, therefore the burden of care is mainly on the family members and other informal caregivers, in most cases the relatives or the neighbours. Within the family, it is mostly women, who take over the care for their aged parents. Some of them may still be employed, others already retired and due to their own medical condition and age unable to provide adequate care for the sick relative. They have virtually no information on the care of persons with dementia and are torn between the responsibility of caring for their parents and their own families. The difficulties they most frequently quote include work overload, their own health problems, financial problems, poor understanding of, and insufficient knowledge about dementia.

The attitude of professionals involved in the care of people with dementia is varied: it is mostly the relatives who first seek contact with professionals. They seek help with the institutions and experts for who they believe they would be best able to provide competent help, whereby they rely on their previous experiences with the experts, information from the environment they live in and above all on their instincts. Institutions they most frequently quote include community health centres, homes for the older people, centres of social work and psychiatric hospitals. In urban environments they would also turn to the non-governmental organisation *Slovene Association of the Alzheimer's Disease and Related Disorders* called *Spominčica* (Forget-me-not), where they provide counselling, self help support groups, telephone help line.

Special training programme is being developed at the Faculty of social work for those who are daily in contacts with people with dementia (relatives, partners, friends, professionals, carers, volunteers).

#### 3.2 Which are the most efficient dissemination tools for sharing information (for targeting the patients / the carers) and why?

While people with dementia and their families in Slovenia are still stigmatised, it is of great importance to promote and educate wider society about dementia. We have to make this theme more ordinary. We have to become aware it could happen to everybody, anytime and

everywhere. We need to cooperate more with media, professionals and science to establish common knowledge and promotion.

### 3.3 What training and education programmes do exist for professionals?

Professionals in institutions (homes for the older people, hospitals) have the possibility to attend different seminars provided by Faculty of social work, FIRIS IMPERL & CO. d.n.o. – Developmental Engineering in the Field of Social Assistance, non-governmental organisation *Slovene Association of the Alzheimer's Disease and Related Disorders* called *Spominčica* (Forget-me-not).

The Faculty of Social Work prepared master degree programme Social work with people with dementia. In the programme special focus is on social work with people with dementia.