

IntegraCare

Programma di formazione
person-centred per
professionisti
multidisciplinari

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**Identificazione di modelli di
successo e casi di studio
sull'assistenza person-centred**

Responsabili:

Athens Association of Alzheimer's Disease and
Related Disorders - AAADR
Tallinn Health Care College



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IntegraCare

IntegraCare: Person-centred care training program for multidisciplinary professionals.

Phase 1 result: IDENTIFICATION OF SUCCESSFUL MODELS AND CASE STUDIES ON PERSON CENTRED CARE

Research implemented by IntegraCare project partners, in the framework of the PHASE 1 of the Intellectual Output - IntegraCare Training Programme.

Leaders:

Athens Association of Alzheimer's Disease and Related Disorders- (AAADR) (Greece)

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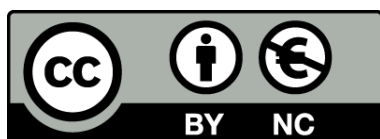
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Sintesi

Questo documento è il risultato della prima fase del progetto IntegraCare, fase coordinata dalla Athens Association of Alzheimer's Disease and Related Disorders e dal Tallinn Healthcare College. L'obiettivo della prima fase è stato quello di identificare, in ciascuno dei paesi partner, nonché a livello dell'UE, modelli di successo e casi di studio sull'assistenza centrata sulla persona, sulla base delle informazioni raccolte grazie a interviste semi-strutturate e realizzazione di focus group. Il lavoro della fase 1 si è concluso in tre fasi:

- Approccio metodologico e proposta di linee guida
- Lavoro sul campo in ogni paese
- Identificazione di casi di studio di successo e realizzazione del report finale

Durante la prima fase i partner coordinatori hanno progettato e condiviso la metodologia da utilizzare nel lavoro sul campo e le linee guida che sarebbero state seguite da ciascun partner. La metodologia includeva la scaletta delle domande che sarebbero state incluse nelle interviste semi-strutturate e gli argomenti di discussione da approfondire nei focus group. Inoltre, sono stati predisposti tutti i materiali necessari per il lavoro sul campo.

Nel report è presente, a complemento, una descrizione del sistema socio-sanitario di ciascun Paese partner per comprendere il contesto dei sistemi di assistenza in cui verrà implementato il programma di formazione di IntegraCare. Ciascun partner ha fornito le informazioni di base sulla struttura del proprio sanitario e sociale e, più specificamente, ha descritto l'assistenza e il sostegno forniti alle persone non autosufficienti.

Il passo successivo è stato il lavoro sul campo. Ciascun paese partner ha completato 5 interviste con cinque diversi operatori sanitari e ha tenuto focus group con 6/8 operatori socio assistenziali



provenienti da contesti diversi. Le registrazioni delle interviste e del focus group sono state trascritte e sono state annotate le relative citazioni. Dall'analisi delle trascrizioni sono emerse, come fondamentali, sette tematiche: 1. Pratiche assistenziali seguite dall'organizzazione, 2. Cooperazione e coordinamento di équipe multidisciplinari, 3. Comunicazione e uso del linguaggio centrato sulla persona, 4. Coinvolgimento della persona e della sua famiglia nel processo decisionale, 5. Inclusività e accessibilità dei servizi di cura per persone non autosufficienti, 6. Strumenti di monitoraggio e valutazione per i servizi di cura, 7. Barriere e soluzioni ai problemi nell'assistenza centrata sulla persona.

Le informazioni raccolte dalle interviste e dai focus group sono state utilizzate nella stesura di dieci casi di studio che dimostrano modelli di successo di assistenza centrata sulla persona. Ciascun paese partner ha fornito due casi di studio che forniranno informazioni dettagliate sulle strategie attuate dai professionisti dell'assistenza e dalle organizzazioni in cui lavorano, nonché su come questi aderiscono ai principi dell'assistenza centrata sulla persona.

Le principali conclusioni che si possono trarre dal lavoro sul campo sono le seguenti.

- In tutti i paesi partner le organizzazioni che forniscono assistenza alle persone non autosufficienti seguono alcune pratiche comuni che comportano la creazione di un piano di assistenza individualizzato per ogni persona, seguendo un approccio olistico all'assistenza, promuovendo l'autonomia e l'indipendenza della persona non autosufficiente e la sua integrazione nella comunità. Le loro pratiche incoraggiano anche la difesa dei diritti della persona dipendente e la deistituzionalizzazione.
- Le organizzazioni di cura in ciascuno dei paesi partner utilizzano metodi specifici per garantire il coordinamento e la cooperazione dei professionisti che fanno parte delle squadre multidisciplinari, si avvalgono della supervisione e tengono frequenti riunioni di gruppo per creare, valutare e adattare i piani di cura di gli utenti del servizio. Gli operatori sanitari condividono le informazioni degli utenti tramite un database.



- Nella comunicazione con persone non autosufficienti, gli operatori sanitari utilizzano un linguaggio centrato sulla persona. Cercano di usare un linguaggio positivo evitando termini dalle connotazioni negative per incoraggiare la destigmatizzazione.
- Durante la creazione di un piano di assistenza e il processo decisionale, la persona non autosufficiente e la sua famiglia sono coinvolte per garantire che i suoi bisogni siano presi in considerazione e che qualsiasi decisione presa in merito alla sua assistenza sia rispettata. Prima di prendere qualsiasi decisione assistenziale, la persona è pienamente informata sui servizi e assistenza che gli saranno forniti.
- In tutti i paesi partner le organizzazioni che forniscono assistenza alle persone non autosufficienti fanno un grande sforzo per essere inclusive e rendere i loro servizi accessibili alle persone che ne hanno bisogno. Ciò avviene creando forti legami con la comunità e promuovendo l'auto-potenziamento.
- Le organizzazioni hanno un monitoraggio e una valutazione regolari dei loro servizi tenendo riunioni e supervisione del personale, nonché utilizzando strumenti di feedback in cui gli utenti del servizio possono valutare i servizi.
- I principali ostacoli e sfide che gli operatori sanitari devono affrontare quando forniscono assistenza centrata sulla persona riguardano la mancanza di risorse umane e finanziarie, nonché i limiti di tempo. Inoltre, la pandemia ha aggiunto una pressione significativa sui professionisti.
- Nonostante queste organizzazioni e professionisti dell'assistenza implementino strategie di assistenza centrata sulla persona, solo in pochi casi sono consapevoli del termine e del suo contenuto.



Section 1: Introduction

Person centered care is a multidimensional concept and currently there is no unanimous definition. It is a concept of care where the focus is the person, not their conditions (Leplege et al., 2007). Individuals are active partners and are supported to make informed decisions about their own care; their values, preferences and goals guide all aspects of their care. Person-centred care is achieved through a dynamic partnership among individuals, important others, and all relevant providers.

The central person-centered care principle is an indicator of quality and aims to achieve the highest levels of equality for people with functional diversity, embodied in fostering personal autonomy, encouraging dependent people's active and healthy lives. This approach guarantees the highest possible level of personal inclusion and allows practitioners to work with an integrated strategy, creating and maximizing synergies without losing sight of this main goal of autonomy and inclusion. From the first interaction with the dependent individual, it is important that the multidisciplinary team carry out a collaborative review of their needs and abilities, which should cover many areas: home life, lifelong learning, health and safety, freedoms, social and community activities.

The IntegraCare project aims at promoting dependent people's personal autonomy, active and healthy lives and empowering the social and health care practitioners to apply critical person-centered treatment models. In addition, one significant goal is to raise awareness of the link between integral person-centered care and the quality of life of dependent people and its core dimensions: emotional well-being, interpersonal relationships, material welfare, personal development, physical well-being, self-determination, social inclusion and rights.

The present report summarizes the activities and results of Phase 1 of the project which is led by Athens Association for Alzheimer's Disease and Related Disorders and Tallin Health Care College. The first phase covers activities which are important for the fruitful implementation of the whole project. The main aim of the Phase 1 is to identify successful models and case studies on person-centred care in the participation countries and at EU level.



Phase 1 commenced with designing the methodological approach and guidelines for the fieldwork. First task was to map the health and social care systems in each partner country in order to gain insight on the care principles and strategies currently implemented. The fieldwork included five interviews and one focus group with care professionals and key persons completed in each partner country. The final outcome of Phase 1 are ten successful case studies of person-centered care.



Overview of social and health care system in partner countries

Overview of health and social care system in Estonia

In Estonia social and healthcare systems are separated. The Estonian healthcare system is regulated by the Health Services Organisation Act. This Act provides the organization of and the requirements for the provision of health services, and the procedure for the management, financing and supervision of health care.

Estonian social system is regulated by the Social Welfare Act which provides the organizational, economic and legal bases for social welfare, and regulates the relations relating to social welfare. Estonian health care system follows the principles of mandatory solidarity for health insurance. Mandatory health insurance has been valid since 1992. The health care is financed from the state budget via the Estonian National Health Insurance Fund, but also it is financed directly from state budget, budgets of different municipalities, by the patient himself and from another source.

The management and monitoring of the healthcare system and the development of health policy is under the administration of the Ministry of Social Affairs. Social welfare is financed mainly through local municipalities' budgets, but in some cases also by state budget, and on a voluntary basis.

Care is provided mainly in nursing homes, but also home care is quite widespread. There are general nursing homes and then there are homes for disabled people. In many nursing homes there is general care and care for disabled people integrated. The different services for different disabled people are fixed by the law and depend on the disability of the person. There are municipality nursing homes but there are also private nursing homes. The same is with home care, some care is provided via municipality but then there are private companies as well. In general, the social care is under the responsibility of the municipality. However, usually residents have to pay in addition.



The professional staff at nursing homes consists of care workers, nurses, and social workers. In many nursing homes there are also occupational therapists, physiotherapists, clergymen. In general, the main work at nursing homes is done by care workers. In addition to care, they also activate clients, give medicine, help the client in everyday life etc. They work on the ground of a care plan that is prepared together with a nurse.

In homes for disabled people, the working professionals consist of care workers for people with mental health conditions, social workers, occupational therapists. They follow an action plan which is prepared by the care worker for people with mental health conditions, together with a client and which also follows a rehabilitation plan that is prepared for each client in a team (physician, social worker, etc).

The general principle for patient's rights is enacted in the Constitution, which states that everyone has the right for health protection. If a patient feels that their rights have been violated then they can appeal either towards the health care provider, Health Agency, Estonian National Health Insurance Fund, or towards the Health Care Quality Control Fund.

All Estonian citizens are provided with pension after their retirement age and in case of officially defined disability, then they can apply for disability benefit. In addition, there is the possibility to apply for certain adjustments at the apartment to keep them as independent as possible, special transportation benefits. Then there are municipality-based benefits, for example one municipality provides alarm button service for their inhabitants, in other municipalities the clients have to pay for that service. Then on the ground of the Assistant device sheet, the dependent people can get reduction from different assistant devices.

There are the following professions in health care and welfare:

Physicians - who can learn at University (only one university in Estonia) for ten years to start working as a physician; Nurses - nurses are registered in the health care register after the graduation of Health Care College. In Estonia nurses' education corresponds to bachelor's degree (level 6).



There are two Health Care Colleges in Estonia where nurses can learn. We also have some nurses with vocational education. They can also work at hospitals, but there is a special course for those to apply for higher education. Care workers – care workers are taught in two Health Care Colleges and in five Vocational Education centers. The curricula are the same independent of the school. They are taught either on level 3 or level 4. There are qualification requirements for the care workers who work at nursing homes. These care workers who work at hospitals have no qualification requirements fixed.

Different profession is for those caregivers who work at homes for disabled persons. For them there are also fixed qualification requirements, and their education corresponds to level 4. They can learn at the same schools as care workers, but their curricula differ.

Overview of health and social care system in Greece

Greece's health care system is a mixed system comprising elements from both the public and private sectors. The national health system provides healthcare benefits/services through a network of public/state providers as well as contracted private providers of primary, hospital and ambulatory care. The system is financed by the state budget, social insurance contributions and private payments. In the public sector, a national health service type of system coexists with a social health insurance (SHI) model, providing free universal health coverage of the population. The past decade there have been endeavors to reform the healthcare system towards an integrated people centred model (Law No 4238/2014, Law No 4486/2017).

In 2011, the National Organization for the Provision of Health Services (EOPYY) was established. EOPYY acts as the sole purchaser of healthcare services for patients covered by the publicly financed National Health System. Primary healthcare is provided by EOPYY- contracted private healthcare providers (doctors, diagnostic centres, private clinics, chronic hemodialysis units; PEDY Units (National Primary Healthcare Network) – public healthcare; state hospitals, health centres, rural and regional medical units of the National Health System (Greek acronym ESY); private health professionals, without a contract with EOPYY, paid privately. Hospital healthcare is provided by



EOPYY contracted private clinics; by state hospitals of the National Health System (ESY), free of charge for health services within the national health benefits basket; private hospitals and clinics.

The private sector includes profit-making hospitals, diagnostic centres and independent practices. In addition, the role of voluntary initiatives, nongovernmental organizations (NGOs) and informal health care networks has increased significantly. The provision of physical rehabilitation, long-term and palliative care by the private (profit-making) sector, voluntary organizations and NGOs has increased. As regards to mental health services, the focus has been on moving services away from institutional facilities and developing community-based services.

In Greece social benefits and financial support are awarded to people who are/ become dependent due to disability and/or age. The organisation responsible for this process is KE.P.A (Disability Certification Centre), the dependent person has to apply for an evaluation of the extent of severity of the disability they live with. The evaluation is carried out by a panel of medical experts, a percentage of disability is decided upon which along with their financial status determine the amount of financial compensation they are given by the state.

The Greek constitution states that all people are equal by law and that all Greek citizens have the same rights and responsibilities. It is stated that people who belong in disadvantaged groups due to disability, age, financial difficulties etc. have the right to be protected by the state and be provided with the necessary care. In 2020 the National Plan of Action for the rights of people with disability was put forward and is to be realized between the years 2020-2023. This plan involves policies that will be put in effect in order to improve accessibility and encourage equality in the sectors of education, healthcare and professional development.

Regarding the provision of care to dependent people, in the past years' efforts have been made by the state to improve accessibility. This was done by setting up programmes called "Help at home" in each municipality. These programmes involve different healthcare professionals who do home visits to people who for several reasons are unable to visit a healthcare facility or live in remote areas. During these visits the professionals involved are responsible for providing care and managing the



needs of each person they visit. Furthermore, the municipalities and regional units have social services offices (Κοινωνικές Υπηρεσίες) and community centres (Κέντρα Κοινότητας) to inform and support citizens.

Finally, care professionals in Greece have a wide range of education and training levels. Their level of education varies according to their professional field. Professionals that require a license in order to practice their profession have to complete a minimum level of education depending on their professional requirements. Specifically, doctors who have to complete six years of medical school in order to be able to practice are considered to have an education level of Master's degree or equivalent (ISCED Level 7), moreover, all doctors go through the process of residency where they receive further training in order to become specialised in the medical field, they choose to work in. Professionals such as psychologists, nurses, social workers and physiotherapists require to have as a minimum a Bachelor's degree or its equivalent (ISCED level 6). Professionals who work as assistants to the aforementioned professions (assistant nurses, assistant physiotherapists etc.) will usually be required to complete a vocational training programme (ISCED level 3, 4). However, care professionals such as formal caregivers do not require a license to practice care therefore, they do not have to meet a minimum level of training.

In Greece training after the completion of the basic educational requirements of each profession is not mandatory and not expected. Training programmes are available for professionals who want to further their knowledge and skills in all care fields. The providers of such programmes are public and private academic institutions as well as other private organisations.

Overview of health and social care system in Italy

Italian Constitution (Art. 32):

The national government is responsible for granting that all residents, in every region of Italy, have access to this benefit package for all essential levels of care.

The health care system in Italy is a regionally based national health service known as Italian National Health System - Servizio Sanitario Nazionale (SSN). It provides free of charge universal coverage at the point of service, only by registering with the Health System; registration is implemented by the Local Health Authority – Autorità Sanitaria Locale (ASL).

While the national level ensures the general objectives and fundamental principles of the national health care system are met, regional governments in Italy are responsible for ensuring the delivery of a benefits package to the population.

The main sources of financing of SNN are national and regional taxes, supplemented by co-payments for pharmaceuticals and outpatient care. Treatments which are covered by the public system and a small co-payment include tests, medications, surgeries during hospitalisation, family doctor visits and medical assistance provided by paediatricians and other specialists. Furthermore, medication, outpatient treatments, and dental treatments are also available. However, public healthcare facilities in Italy vary in terms of quality depending on the region.

There are also many private hospitals in Italy that boast excellent facilities; although the comfort of extra services (i.e. availability of single room, meals) at private hospitals are generally superior, the quality of care is likely to be similar to that of public hospitals and their treatments can be prohibitively expensive without the assistance of a private health insurance policy.

Concerning the long-term care (LTC) system in Italy, it is characterized by a high level of institutional fragmentation, as sources of funding, governance and management responsibilities are spread over local (municipalities) and regional authorities, with different modalities in relation to the institutional models of each region. The actors directly involved in the organization of LTC services are municipalities, ASLs, nursing homes (residenze sanitarie assistenziali, RSAs) and the National Institute of Social Security (Istituto Nazionale Previdenza Sociale, INPS), but other players are involved in planning and funding these services – i.e. the central state, regions. Additionally, in Italy a significant share of LTC expenditure is funded directly by households. Moreover, a large part of



caregiving is still provided by informal carers, especially in regions where public services are less advanced and in families that cannot afford the cost of private services. Privately purchased home care is often provided by immigrants.

In Italy, public long-term care for older persons includes three main kinds of formal assistance: 1. community care, 2. residential care and 3. cash benefits. The SSN plans and manages, through ASL, home health-care services by the the so-called ‘integrated domiciliary care’ (assistenza domiciliare integrata, ADI)– and other health services provided in residential settings. Personal social services, both domestic and personal care tasks provided at home (servizi di assistenza domiciliare, SAD) and institutional social care are managed at a local level by municipalities, although this should be planned in coordination with the ADI.

Long-term care is delivered by both public and accredited private providers of health and personal social care. The health care services provided by the SSN are free of charge, whereas social care is means-tested and users can pay up to the full cost of it. The National Institute of Social Security provides a cash benefit (indennità di accompagnamento) to disabled persons, independent of their financial situation. This cash benefit is not directly linked to an obligation to purchase goods or services, and it is aimed at improving one’s personal condition and can thus be used to compensate the household for informal care. Nevertheless, the indennità di accompagnamento is usually considered part of LTC expenditures in Italy, unlike invalidity pensions. Other cash benefits are provided by some municipalities, but these are usually means-tested. LTC in Italy is also characterized by a wide variation among regions and areas in both funding levels and the structure of the services provided.

Finally, care professionals involved in provision of care for dependent people in Italy may be divided in two main different areas: a. health care:- nurses Level 6, -physiotherapist Level 5, obstetrician Level 5, socio-health care: - educators Level 6, - oss (operatore socio-sanitario), – social-health operators Level 4, informal caregivers Level 3 (or less).



Overview of health and social care system in Spain

The social security system is the main institution of social protection. Spain employs a universal health care system. Provision of health and social care services are decentralized, and thus the responsibility of several autonomous communities. The following health services are covered: medical care, emergencies, rehabilitation and medicines. Moreover, there are social services, which support people with concrete vulnerabilities.

Organizations, which support people with disabilities, can be both public and private. There are several ways to get the funding needed to help. The main sources of funding are taxes and private companies such as banks. For instance, our organization is an NGO financed by taxes, subsidies and the private sector.

Professionals who work taking care of dependent people have a diverse educational background. There are people with basic studies such as home workers, nursing assistance or caregivers. There are also people with higher education. The main professional profiles are psychologists, physical therapists, nurses and social workers.

If you are dependent, you can apply for long-term care due to your age or because you suffer from an illness or disability, you cannot carry out your daily basic activities without the help of another person.

The state protects dependent people through the law of dependency which reassures that this group is well-treated and no-one damages their rights. People with disabilities can access a variety of services and education for free or with a reduced cost.

Financial benefits vary according to the person's degree of dependency, but these are only available if the beneficiary does not receive other similar benefits and it is impossible to offer support through specific services. Financial benefits linked to services: available for dependent people who cannot access public or state-assisted care services.



The Ministry of Education is responsible for the regulation of health professionals' undergraduate training and, in association with the Ministry of Health, of postgraduate training and human resources planning. These ministries are also responsible for lifelong learning with a great variety of courses, seminars and specialities.

The professionals who work taking care of dependent people can be trained on the following educational programs divided in three different levels: 1 Vet education (nursing assistant, familiar assistant and others), 2 undergraduates (psychologist, social workers, doctors, physical therapists and others) and 3 postgraduates (neuropsychologists, specialized doctors and others).

Overview of health and social care system in Poland

1. General context of the social and healthcare system

The Polish **health care system** is based on the insurance model, i.e. the common health insurance. Article 68 of the Constitution of the Republic of Poland states that "everyone has the right to health protection". Citizens, regardless of their financial situation, public authorities ensure equal access to health care services financed from public funds. The National Health Fund (NHF) finances public health services, provided by public and non-public health care institutions, which operate on the basis of an agreement for the provision of healthcare services (so-called contracts) signed with the National Health Fund. There are also numerous private commercial entities providing health services financed from patients' own funds.

Social welfare generally is an institution of the state's social policy, aimed at enabling individuals and families to overcome difficult life situations which they are unable to overcome, using their own powers, resources and possibilities. Public social welfare is organized by governmental administration bodies (minister competent for social security, voivodes) and local government administration (voivodship/regions, poviats nad gminas). These public bodies, when implementing social welfare tasks, cooperate, on the basis of partnership, with social and non-governmental organizations, church organizations, religious associations, and natural and legal persons. NGO play an important role in the health and social care system in Poland. According to the report of the Central



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Statistical Office (2018), over 20 percent. institutions providing social services (in areas such as social assistance and childcare, social and vocational integration, health care, education, culture and sport) are run by the non-profit sector. Standards for the functioning of organizational units of social welfare, standards for individual types of services, qualifications of persons providing social services are defined in the form of regulations by the minister for social security (applicable to public entities or private entities whose activities are financed from public funds).

2. Organisations that provide care and support to dependent people

Care and support for dependent people in Poland is organized by institutions belonging to three sectors:

- **Public sector:** these are public entities, financed from public funds
- **Private sector:** these are entities operating in various legal forms, operating on a commercial basis (for profit), participating in the process of satisfying the needs of the society. Their services are financed on market terms, and sometimes entities obtain public funds.
- **Social sector:** these are non-governmental and religious organizations, and social cooperatives, the operation of which is not aimed at profit. They obtain public funds for their activities, funds from subsidies, private sponsors, and partial payments from service users.
- Funding for support for dependent people comes from various sources:
- **Public funds** (from the state budget and local government budget) - this applies to public entities (organizational units performing public tasks in the field of social services and non-public entities (e.g. NGOs) implementing public tasks under public subsidies obtained
- **National programs financed from the State Budget** (e.g. Senior + Program, Government Program for Social Activity of Elderly People for 2014-2020)
- **European Union funds** - under national and regional programs under the 2014-2020 financial perspective (based on the Guidelines for the implementation of projects in the field of social inclusion and combating poverty with the use of the European Social Fund and the European Regional Development Fund for 2014-2020 with on January 9, 2018)
- **Private funds** - sponsors, own contributions, etc.



The following professions are listed among specialists dealing with the care of dependent people:

- Carer (for elderly – PQF / EQF Level 4, medical caregiver –Level 5)
- Therapist (PQF / EQF Level - 4)
- assistant to a disabled person (PQF / EQF Level - 4)
- Psychologist - (PQF / EQF Level – 8)
- Physiotherapist (PQF / EQF Level - 4)
- A nurse (PQF / EQF Level - 4)

3. Support and/or benefits for dependent people provided by the state

Social and financial support or benefits for dependent people includes:

- Different financial benefits to individuals and families: Care allowances, Housing allowances, Permanent allowances, Specific allowances.
- Nursing services or specialized care services provided at home of a dependent person (due to age, illness or other reasons, it requires the help of other people, a single person): Nursing services include help in meeting everyday life needs, hygienic care, care recommended by a doctor and, if possible, ensuring contacts with the environment. Specialist care services are services tailored to the specific needs of the type of disease or disability, provided by people with specialist professional preparation.
- Co-financing for disabled people and their carers to participate in the rehabilitation camp.

The local government (gmina and powiat) is responsible for the organization of care services and specialist care services, which determines their scope, period and place of provision. Care services are the local government's own task, and specialized care services - a commissioned task.

4. Training of care professionals

On the basis of the Regulation of the Minister of Labor and Social Policy of April 17, 2012 on specialization in the profession of **a social worker** (Journal of Laws 2012, item 486), the minimum



curriculum for the 1st and 2nd degree of specialization in the profession of a social worker has been defined. Training in the framework of these specializations is conducted by entities who have received the approval of the Minister of the Family, Labor and Social Policy to conduct trainings in the field of specialization in the profession of a social worker. Obtaining the professional qualification "social worker" takes place after completing the training (1st and /or 2nd specialization) and passing the exam by the regional examination commission for the degrees of professional specialization of social workers.

In terms of other specialties, thematic areas related to the development of competences in the care of dependent people, there are many trainings offers on the market (in the post-formal way) with different duration and organization. Some of them are financed from subsidies (e.g. subsidies from the state budget) or EU subsidies.



Section 2: Method

Ethics

All participants signed informed consent forms before the data collection process started. They were informed about the aim of the project as well as their right to withdraw their participation at any given time. They were also informed that their responses would be recorded using an audio recording device and that their data are be confidential and only the researchers of the IntegraCare project will have access to it.

Interviews

Participants

Each partner country conducted five interviews with five care professionals. Each partner involved professionals from different care professions in the interviews. If a partner only had access to professionals that work in the same discipline, then they involved professionals that have worked in different care settings and/or with different populations of dependent people (e.g., older adults, physical or mental disabilities etc.). Twenty-five care professionals were interviewed in total.

Procedure

Five semi-structured interviews with care professionals were conducted by the researchers in each partner country. The interviews were carried out in the form of one-on-one sessions between the researcher and the interviewee. The interviews were done either in person -when the circumstances allowed it- or via Zoom/Webex/Skype platforms. The duration of each interview was 45 minutes to 60 minutes and time was allowed for each interviewee to answer each question without rushing. At the start of the interviews the interviewer provided the participant with informed consent forms and explained the process of the interview. Then the participants were asked to fill out a document with their demographic information. The main part of the interview followed where the interviewer asked the open-ended questions. After each question the participant was given some time to answer, if their answer did not provide adequate information the question was followed up with probing questions (eg. please elaborate; please give an example) to encourage the participant to expand on their answer.



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Materials

Informed consent forms that contain information about the interview process were provided as well as a document with questions about demographic information and questions about their level of education and years of experience in a care setting.

The interview included open ended questions that focused on the following seven topics:

- Care practices followed by the organisation: how they are implemented by each type of professional and do they adhere to the principles of Person-Centred Care
- Multidisciplinary teams: cooperation and coordination between different professional fields
- Communication: use of person-centred language, attention to non-verbal communication
- Involvement of family and informal caregivers: how family members become be involved in a care plan and support provided to them
- Inclusivity and accessibility: practices are undertaken to make care accessible and inclusive to a diverse population of dependent people
- Monitoring and evaluation: tools used for the evaluation of care practices
- Barriers and solutions: how professionals experience common barriers in person-centred care and potential solutions to them.

Focus group

Participants

Each partner country conducted one focus group and each focus group included six to eight care professionals. Each group should involve participants from at least three different care professions. If a partner did not have access to professionals from different disciplines, then they could involve professionals that have worked in different care settings (*see participant section in Interviews*).



Procedure

The focus groups were conducted either in person or via Skype/Zoom. The focus group duration was approximately 60 to 90 minutes, time was allowed for each topic to be discussed adequately by the participants. Two researchers were present in the focus group, one guiding the discussion by providing the relevant topics and the other taking notes of the process and recording it.

The focus group began with a brief presentation describing the project and the objectives, followed by asking the participants about their knowledge of PCC and giving them a general definition of the theoretical framework of PCC.

Materials

Informed consent forms that contain information about the focus group were provided as well as a document with questions about demographic information and questions about their level of education and years of experience in a care setting. A small presentation that includes the definition of person-centred care and the main characteristics it involves was prepared and printouts were given to the participants.

A focus group guide with the topics was created to guide the focus discussion in order collect the relevant information. The focus group guide follows the same general topics as the interviews (*see Material Section of Interviews*).



Table 1. Field work participants' information

	Greece	Spain	Italy	Estonia	Poland
Number of participants for Focus Group	6	12	6	6	6
Professions for Focus Group	Psychologist Neuropsychologist (Scientific Supervisor) Nurse Neurologist Social worker Physical therapist	Social Worker Neuropsychologist Nurse assistant Speech therapist Physical therapist Coordinator Psychologist Occupational therapist Social educator	Nurse Chef Social-health operators (different structures)	Director of nursing home Chief nurse Care workers Director of social apartments	Psychologist Social worker Therapist Coach Physiotherapist
Number of Participants for interviews	5	5	5	5	6
Professions of participants of interviews	Neuropsychologist (Scientific supervisor) Nurses Psychiatrist Social worker	Social worker Coordinator Psychologist Sexologist Social worker	Physical therapist Entertainer Social-Health Operator (different structures)	Care workers	Psychologist Social workers Therapists



Section 3: Fieldwork Results – Successful case studies of person centred care

Estonia

Case Study 1

This case study gives an overview of a working style/ method/ approach/ paradigm of managers. In this study we describe the paradigmatic views of head nurses and managers from hospitals and nursing homes taking into consideration the main aspects of person- centred care approach.

No uniform model/ strategy exists. Head nurses and managers of nursing homes follow more client-centred approach. They value the disabled person. Disabled person is no longer an object, but a human being with all his characteristics, wishes, fears and expectations. However, the person centred/ human centred approach is mainly project based for there are no enacted rules or regulations. The managers refer to the implementation as a new paradigm relying on their own reflections caused on the ground of the reading and heard knowledge. They prefer the term “client” and not so much the term “human”.

The term “client” involves autonomy and freedom. The term “human” has patient-centred connotation. One problem is the lack of integration, it includes transition from health care system to social system or vice versa – there is a so-called grey area. The terms that specialists use when referring to disabled people are different, some use human, some use person, others client or patient.

One of the main factors to illustrate person-centered care is communication and teamwork. Head nurses and managers of nursing homes try to manage information flow and share information to others. However, it is not formally regulated. It works on informal bases. But head nurses and managers always share important information to other members of the team. So, the managers value teamwork and they see the team as a group of people including following specialists: doctor, nurse, care worker, clergy man, physiotherapist, dietary nurse, social worker and one representative from the management. But they do not include the disabled persons or their relatives. And again, the biggest problem is the information flow between systems, there is no integration between health care and



social care system. What happens to a disabled person who has to be transferred from hospital to a nursing home?

Communication/ small talk is important, but head nurses and managers do not often meet dependent people. So theoretically they pay not so much attention to direct communication but to empowerment, which is important for the sake of a person. For example, they do not say: do not drink but they explain what bad should drinking bring along. Also, it is important to understand people with different cultural backgrounds, and they wish to have more topics on cultural varieties/ different cultural systems in educational curricula.

Involvement is often a synonym of activation, and managers are not responsible for activating the disabled person. Therefore, they have not paid much attention to the involvement of a disabled person, they point in that issue to care workers. Sometimes clients are involved into the preparation of a care plan, sometimes they are not involved. Involvement depends on people, there is no direct rule or must to involve client or to ask the client's opinion.

Head nurses and managers appreciate the quality of services. Services are good, but accessibility depends on information flow and systems flexibility. Co-operation between other specialists is good but not regulated. Cooperation and teamwork are better in smaller areas where people know each other, and more complicated is it in bigger cities, in capital where you have to follow procedure, but this is not enacted.

Hospitals and nursing homes collect feedback from clients and their relatives. That is a regular procedure. Some places also collect feedback from employees, and this happens mainly due to the development interviews. They analyze the results, and some amendments have been made. The main problem the managers see is that there is no integration between systems, but also data protection law is an obstacle. The problem should be solved on a national level.

Case Study 2

This case study gives an overview of a working style/ method/ approach/ paradigm of care workers. In this study we describe the paradigmatic views of care workers from hospitals and nursing homes taking into consideration the main aspects of person-centred care approach.

No uniform model/ strategy exists. Care workers follow a task centred approach and due to the lack of time only basic needs are met. However, like managers also care workers value the disabled person.

One of the main factors to illustrate person-centred care is communication and teamwork. Communication flow and teamwork is not formally regulated. It works on informal bases. Sometimes information is shared with care workers and sometimes not. Care workers value teamwork. They see a team as a group of persons which includes a care worker, nurse and a disabled person. The team's aim is to satisfy client basic needs.

Communication/ small talk is important. They always say hello, introduce themselves, explain what they are doing. However, sometimes reactive language is used, sometimes they are irritable, have no time to sit at the bed and simply listen to the client. But they understand how important listening is, although it is excused due to the lack of time. Care workers can use different tools of alternative communication. They do not pay attention to cultural or religious background. All people are more or less similar. The only difference is language, and they divide disabled persons according to native language: either Estonians or Russians, and as care workers are older and they have learned Russian at school, they see no problems in connection with "cultural background".

Involvement is often a synonym of activation. For example, involvement is that when a disabled person wants to open a bottle, the care worker activates him/ her by encouraging him/ her to do it himself/ herself. If client himself does not speak then additional information is received from relatives. However, the involvement of relatives is not effective if the relatives themselves are not interested. Often the attitudes of the relatives are problematic – too much is expected from the hospital and nursing home. Not all workers think that the client's involvement is important.



Care workers are often not involved into teamwork and they do not see the whole picture.

The system for feedback is inadequate. There is no regular collection of satisfaction feedback from clients. There are some development interviews but again no feedback will be given to care workers. The care workers get feedback from their clients via observation, if they do their work well, they are praised if no complaints are made. The problem is resources meaning money and time and also knowledge. One solution is training, and more care workers.

Greece

Case study 1: Home Care setting

To begin with, this case study is describing a home care programme for people with dementia and their families/caregivers. The team is comprised by healthcare professionals from different disciplines, that is psychiatrists, nurses, psychologists, physical therapists and social workers. In this programme, they receive requests from families/informal caregivers as well as referrals from other healthcare professionals. Their first step is to contact the person who made the request and make an appointment to meet them, look into the request and evaluate the situation. This first appointment is conducted by a psychiatrist and a social worker. Following, the requests and needs of the persons are discussed and the appointments are allocated among the healthcare professionals.

The healthcare professionals operate and manage their work as a team. They follow a protocol for managing and allocating the requests they receive and work closely together for the best interest of the service users. Their values include equality, authenticity, honesty, inclusivity, respect and “caring” towards each other and the people they provide care to. They try to build trust and solid relationships with persons and their families/caregivers and to create a comfortable and optimistic environment for them. Their services are open to everyone and they value the feedback they get from the users. They advocate for the rights of the people with dementia and their caregivers and empower them to be autonomous to the extent they can. They provide them with advice and instructions to maintain daily functioning and good life quality at each stage of their path. They value and respect the person's preferences and decisions and are there to provide support and guidance. Finally, they are connected with other organizations and make referrals when necessary.

As regards to the involvement of the family/informal caregivers, the majority of the requests are made from the informal caregivers/family so they are the ones to make the initial contact in order to evaluate the request. The information about the person with dementia is obtained both from the persons themselves and their caregivers/family members. The healthcare professionals always try to obtain information from the person; only when this is not possible, they are talking with a reliable caregiver. So, they also get information from the caregiver and talk to the person to introduce themselves and make them feel comfortable with them. When making decisions, the strategy followed is participatory



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decision making after informed consent. Specifically, the professional informs the person about the available choices, their advantages and disadvantages and they come to a decision together. The healthcare professional can make recommendations, but the decision is always taken by the person of interest or the family. As a rule, the person themselves should make the decisions and only when they are not capable of doing so, the family/caregivers take over.

It is important for the healthcare professionals to build trust and a good relationship both with the person and their family/caregivers. A means to achieve this is by providing adequate information, direction and explanations for the situation as well as the actions that need to be taken. This cooperation is facilitating the professionals' work and ensures the high quality of care the users receive. Cooperating with the caregivers is a significant aspect in providing care. However, the professionals pinpoint that they should always be cautious of the requests made by the family/caregivers, e.g., for malingering, and not jump to conclusions before their own evaluation of the situation and the person. Finally, every professional should set their boundaries and be clear on what they can and cannot provide.

Communication is significant in order to build and maintain a good and productive relationship both with the person and the family/caregivers. The healthcare professionals are always mindful about the fact that the users are mostly people with dementia at the more advanced stages and in order to communicate with them they always use simple and easy to understand language. They talk slowly and loudly to ensure that they are being understood. Furthermore, they make use of positive language which means they try to use words that do not stigmatise the people in their care; they avoid using negatively-charged words that refer to their capacity and might make them feel dehumanized. What is more, they often work with people who have difficulties in verbal communication due to the nature of their disability. In these cases, the healthcare professionals try to make use of non-verbal communication. They stress the importance of making eye contact with the user and the implementation of arts as a means of self-expression and communication. Nurses try to observe the service users to notice any physical changes in their bodies and their mobility as well as their reactions and expressions. Moreover, the professionals try to build a good relationship with the people they work with by having an optimistic and pleasant attitude. They use multiple ways to make the



communication more enjoyable, such as being smiley, making jokes and use humor and singing songs with the service users.

The home care programme is an inclusive service made to provide care to people who are not able to leave their house to seek care at a memory clinic or a day centre due to mobility and other issues; therefore, the professionals that work in this service are always trying to find ways to provide care to all the users. The professionals try to prioritize users who have more immediate needs when programming their visits. The home care service is a free service which means that all people will be able to have access to it without any financial burden.

As regards to communication and coordination of the team of healthcare professionals, it is evident that there is a strong sense that the professionals are a team. They are encouraged to work together as much as possible and make visits in pairs. The organisation promotes and enhances positive and productive relationships between professionals by emphasizing the importance of cooperation in their personnel selection, being organised, having specific go to persons for the issues that arise, and by fostering a positive and supportive environment for the employees.

A group meeting is held once a week with all the professionals present. There they discuss the new requests, the progress of the people they already visit, they make care plans and allocate the appointments among them based on each persons' needs. In addition, they share and discuss issues that might arise, challenges they face and ask their colleagues for advice if needed. There is a specific person, a social worker, that is in charge of receiving and recording the requests based on the discipline the person is in need of. The decisions are made by the whole team. Furthermore, the professionals make referrals to each other when they evaluate that a person needs it or they need extra information to fulfill their role. When someone in the team gets a referral, they make sure to contact and discuss with the professional that made it; always provided they have permission from the person concerned. There are distinct boundaries to what is the expertise and field of work of each professional which is something they have reported to be important for maintaining a good relationship with each other.



As for information sharing, there is an online database where the professionals from all disciplines keep complete records of the persons they visit and their progress. All the team members have access to this information and are able to read what their colleagues have been working on with each person. The nurses keep an additional excel file record which they complete after each appointment. In this file they write in detail what services they offered in each visit. The database records made by each healthcare professional are also used as a means to monitor their work and track the progress made with each person. They use psychometric tools to monitor the progression of the service user's cognitive abilities and a database with photos to monitor physical changes (wounds). Moreover, they encourage the service users to provide them with feedback either positive or negative about the care service both in person and on the Association's social media and the newsletter.

Finally, despite the fact that healthcare professionals are able to provide personalized care they still face some barriers. Specifically, the demand for the services is very high and the personnel is not enough to respond immediately to the requests. For this reason, there is a waiting list and the visits are limited to once a week even though some people may need more than that. However, the organisation is supportive for any problem that arises and tries to solve everything with teamwork and collaboration.

In conclusion, the home care programme is a service that adopts and implements person centred practices. When asked, most healthcare professionals were familiar with the term person centred care and had an understanding of the term to a certain extent. They mostly emphasize taking a holistic approach in providing care. However, they seem to focus on one domain of what the person centred care means which also derived by the term per se; that is providing personalized care focused on each individual's personality, needs experience and story; despite the fact that they do use person centred practices they are not fully aware that these practices fall under the term of person centred care.



Case study 2: Day Care setting

This case study describes the care practices in a Day Care Centre for people with Dementia that is part of a larger organization. The Day Care Centre offers different types of services such as a memory clinic, psychosocial interventions, counseling, physical therapy and various activities for older adults. The professionals that work in the centre include, neurologists, neuropsychologists, psychologists, social workers, nurses, physical therapists and administrative personnel.

The professionals in the day care centre follow a specific protocol when it comes to their care practice. When a new service user comes to the centre they have to follow a certain process in order to find the best care plan for them. Initially, when a new user comes to the centre, they are administered a neuropsychological evaluation by a psychologist in order to assess their cognitive abilities. This is followed up by an examination with the neurologist. After the assessments are completed a diagnosis is made and then the neurologist offers the option to the user to take part in the psychosocial intervention groups that take place at the day care centre.

When creating a care plan for each individual, the healthcare professionals of the day care centre take into consideration all the characteristics and needs of the person including their social and financial situation, their mobility needs, the type of assistance they have access to etc. The healthcare professionals working at the centre always show empathy towards the problems the users face, offering individualized care, cooperation with the people and looking at the person as a whole rather than focusing on the disability.

During this process of making the care plan both the person and the caregiver/family members are involved in the process of evaluation, decision making and intervention. The healthcare professionals of the centre interview both the person of interest and the caregivers/family members in order to acquire enough information and be able to formulate a well-rounded view of the situation. Especially when a person is not capable of providing a lot of or no information, the caregiver is the one that will provide information about the person, their habits, their interests and the difficulties they face. The social environment of the person with dementia is also evaluated through interviews and specific



documents, to make sure they are safe and not being exploited or harmed in any way. It is important that the person providing information is reliable and has good intentions for the person with dementia. The person's lifestyle, current state and preferences are always taken into account when proposing interventions. The person of interest is always encouraged to take part in this process to the extent they are able to.

The users and their families are kept informed and are also asked to provide feedback about their experience using the services. Building a good relationship with the person first and the family members/caregivers is a factor that can have a positive impact on the user.

The Day Care Centre professionals focus a lot on communicating with the service users and helping them feel like they are being understood. When interacting with a user who has difficulty in communicating their needs the care professionals try to use different methods to improve communication. They use simple explanatory language when talking to the users, they give the user enough time to understand what is being said to them and repeat as many times as necessary. If a person is struggling to say the things they want to and have trouble speaking clearly the centre's professionals try to help them by suggesting words to them and trying to paraphrase what they are trying to say. If verbal communication is not possible, the professionals at the Day Care Centre rely on using eye contact, touch and art as a way to communicate with the service users. They try to learn things about them, about what hobbies and interests they have so they can have things to talk to them about to entertain them and keep them feeling calm. They try to be expressive and use a gentle tone and gentle movements so they don't aggravate them.

The professionals of the Day Care Centre are aware of the impact that the language they use can have, they try to implement positive language in their care practices. They note that it is important to see the person and not the disease thus when they refer to the people they work with they avoid using terms such as patient, demented, disabled or other terms that are emotionally charged and focus on their disability instead of the person as a whole. They try to refer to the people in their care using their names or neutral terms such as people with dementia or people with problems in their cognitive functions in order to not make them feel marginalized and insulted.



The Day Care centre provides services to a large number of users on a daily basis, all services are accessible to people as they are free. However, due to the large number of requests for appointments not all users' needs are easily covered by one centre. As a result, the professionals in the day care centre try to maintain an open communication with the other day care centres of the company as well as external care services in order to distribute the requests and manage to cover all the existing needs of the users.

Besides redistributing needs to other services, the professionals at the day care centre use different methods to reach potential users, they have regular calls with the users as well as communication using online platforms. This way they are able to keep in touch and carry on offering activities such as the psychosocial interventions to people who are unable to come to the centre because they live far away or because of health problems that do not allow them to move. In the case that certain users do not have access to the internet, the healthcare professionals try to find alternative ways to offer them the opportunity to participate in the center's activities by having people pass by the user's house to give them cognitive training exercises and doing them by the phone.

The healthcare professionals composing the team focus a lot on the value of teamwork and cooperation in order to provide high quality services for the users, also for maintaining a good working environment. They value the role and contribution of each different discipline and professional and view their services as a collective effort where everyone is inseparable to the others. In order to keep the team bonded, they communicate often with each other, they have a viber group for personal communication, they try to spend time together and organize activities such as trips, meals and exercise groups. Finally, they highlight the importance of discussing the issues that arise both among them and with the supervisor and the importance of having clear boundaries between the different professionals and fields.

Once a week the team of healthcare professionals has a staff meeting. In this meeting they discuss the difficulties they faced during the week and make decisions on these matters. Specifically, they gather all the information that the professionals of the different principles have collected about each person; based on all the information they discuss and take collective decisions about the intervention plan



they will suggest. Furthermore, there is room and time for everyone to express their thoughts and concerns and receive feedback from the team and the supervisor. In addition to the weekly staff meetings, there is external scientific supervision for the healthcare professionals which takes place once a month.

As for information sharing, the healthcare professionals keep detailed daily journals regarding what happens in the day centre in a common excel drive. They also use this drive as a means to communicate with each other, they write comments and messages for their colleagues. All staff members have access to the file and check it every time they are on a shift. The users' records are kept in an online database by all the healthcare professionals.

Moreover, the organisation acknowledges the hard work the healthcare professionals do to provide services to the users and supports them by being there for them and having persons in charge to guide the professionals for the issues that arise.

In the Day Care Centre, the progress of the service users is monitored by having yearly neuropsychological and neurological assessments in order to keep track of any changes in their cognitive abilities, their neurological symptoms and general health condition. Moreover, they try to keep up with any changes in their social, family and financial situations so they can have a complete picture of the progression of their users. Different methods are used for evaluating the centre. Firstly, they have an external supervisor they have regular meetings with where they discuss any problems that arise in the service and try to find solutions in order to improve the care they provide. Furthermore, even though they do not have formal evaluation tools, they encourage the service users to give feedback by phone or letters as well as creating evaluation documents to measure the satisfaction of specific events that take place in the day care centre like the caregiver support group meetings. Overall, due to the friendly and familial nature of the day care centre the service users always feel welcome to bring up any issues or complaints they might have about the services in an unofficial way as well as to express their satisfaction through small actions like verbally thanking the staff of the centre or writing positive things in the newsletter.



Finally, the barriers faced in the provision of personalized care by the healthcare professionals mainly concern space capacity, financials and human resources. More specifically, the day centre operates in a small space for the number of users they serve. The number of users visiting the centre and integrated in the psychosocial interventions is very high which makes it demanding for the healthcare professionals available. Due to financial reasons the day centre should serve a high number of users to maintain its presence. The way the professionals handle these difficulties is mainly by being flexible, adaptive and willing to provide high standard personalized care. Finally, they report that the organisation does not interfere with their professional work.



Italy

Italian Case Study – Residential Structure for elderly people with different diagnosis (physical disabilities, comorbidities, dementia, etc.)

SCENARIO: This case study analyses the situation of social-health care approach in an Italian residential structure for elderly people with different diagnosis (especially physical one).

The user-centred approach is the ideal basis of the care system to be adopted, but it isn't structured as a specific model nor with defined protocols. Coordinator, nurses, social-health professionals and all operators working in the residential structure (i.e. physiotherapist, chef, entertainers, etc.) are focusing their intervention always taking into account the well-being, the needs – clinical, practical and emotional – of the dependent people are the focus of the intervention, but no official strategy exists. All the care professionals are active for the final improvement of quality of life of the elderly people they care for, that they kindly named “hosts” and not “users” or “clients” or “patients”.

One of the main obstacles of the user-centred is the lack of human resources and related lack of time: these situations sometimes care professional have to choose between practical tasks and human relation, so, in these situation, they perceive the impossibility to put the human and emotional aspects of each individual at the center of care intervention, because primary needs have the priority. Above this, in the last one year and half, COVID emergency put the care professional in an enlightened position, making them the substitute family of their care receivers, but on the other side, increasing the number of tasks to be performed to guarantee the sanitary security of so fragile people.

In this critical and extraordinary situation, also the integrated and multidisciplinary work become impossible or very hard to put in practice: less time and more procedures to implement, less professional because of the contagious and more tasks to carry out, no possibility to have any kind of contact with the external and increase of the need to relationship within the isolation of the residential structure. Before COVID emergency, coordinator, doctors, nurses, social-health operators, animators,



etc. were used to meet weekly in a specific assigned space named “équipe”; the “équipe” is the multidisciplinary team that has two main objectives: to allow the entering of the care receiver in the social-health system and to accompany him/her in the integration process in the residential structure. The équipe prepares the P.A.I. (Individualized Assistance Plan) with, which its structure, guarantees each guest a tailor-made care service.

A multidisciplinary team guarantees personalized and complete assistance both for the use of internationally validated rating scales as well as all the information collected by the various services.

The objective of this program is the enhancement of the individuality of the guest who is evaluated in its complexity, building around him, and not vice versa, the support activities and allowing, thanks to the multiplicity of interventions of every moment of the day.

To continuously monitor the situation, evaluate the results of the activities/tasks implemented and, if necessary, make any changes to the intervention plan and/or to adapt the activities to the new situations that have emerged in the meantime.

Due to COVID restriction, it's more than one year that the équipe is unable to meet so they must substitute face-to-face weekly meeting with WhatsApp group, emails, phone or video calls, but it seems not so efficient and effective because of the lack of direct contact, time, possibility of sharing feeling in real time.

As for the teamwork, also the communication modality is changed, both the internal and the external one. With the suppression of the meeting in person and the impossibility to directly receive familiars, the coordinator represents the point of reference and information for actors involved in care relations. This process isn't formally regulated, but everyone refers to the coordinator in the way he/she prefers and after the coordinator manages information flow and shares it to all the others.



Involvement of the familiar, especially of dependent people with dementia or any kind of mental disability, is assumed as fundamental in the decision-making process. The family plays a crucial role at the beginning of the care path, but they are constantly updated and consulted before any decision or change; they are the one taking the final decision for their parents. Generally, families are in charge of entering their parents in the residential structure, accompanying and supporting them, with the cooperation of the general practitioner, during the process. They have to explain to their parents about any steps and about what's going to happen to them with simplicity, clarity and honesty. The access to care services is managed by the Italian National Health System (SSN) and is regulated by National Law. The procedures are quite complex for end users, so they are managed by familiars and general practitioners.

In conclusion, it's possible to affirm that the lack of time, the isolation from the outside, the overlapping of tasks and the fact that caregivers are representing the whole world of people living there are the main barriers to a real integrated user centred approach. To have more time and the possibility of better knowing and deepening each single case, seems to be a preliminary step to improve the quality of work, for care professionals and the quality of life, for care receivers.



Italian Case Study 2 – Residential Structure for people with dementia and Alzheimer’s

SCENARIO: This case study analyses the situation of social-health care approach in an Italian residential structure for people (especially elderly one) with dementia and Alzheimer.

The user-centred approach isn't structured as a specific model nor with defined protocols, but it is fundamental considering that each user has specific medical needs and isn't able to directly communicate it in every moment. All figures and operators working in the residential structure (i.e. physiotherapist, chef, entertainers, etc.) are focusing their intervention always taking into account the well-being, the needs – clinical, practical and emotional – of the dependent people are the focus of the intervention, but no official strategy exists. All the care professionals are active for the final improvement of quality of life of people they care for, even if they're not able to completely understand where they are or with who.

The lack of time - and eventual accidents - are representing the main obstacles of the user-centred approach application in real contest: this situation makes sometimes care professionals have to put first practical and medical tasks instead of human aspects: in such a choice the caregivers perceive the impossibility to put the single persona at the center of care intervention. But, it's important to underline that, with Alzheimer patients and, in general, dementia, the aspect of personal communication remains in the daily protocol because it is one of the “medical tasks”, fundamental for the treatment of the pathological condition.

Concerning the importance of human relation between caregivers and care receivers, COVID emergency has only enforced the centrality of the role of caregivers, that, more than before, now represent a referring figure substituting the family of their care receivers.

As in all other social and health services, the critical and extraordinary situation of the pandemic, made the integrated and multidisciplinary work harder to be put in practice: different shifts, more specific new procedures to implement to assure a safety work, unexpected accidents, less professional because of the contagious, no possibility to have any kind of contact with the external and the increase



of the need to relationship within the isolation of the residential structure. Before COVID emergency, coordinator, neurologist, psychiatrist, diabetologist, but also nurses, social-health operators, animators, etc. were used to meet weekly in a specific assigned space named “*équipe*”[*see before the definition of équipe*; the “*équipe*” is the multidisciplinary team that has two main objective:

1. to allow the access of the care receiver in the social-health system and to accompany him/her in the integration process in the residential structure. The *équipe* prepares the P.A.I. (Individualized Assistance Plan) with, which its structure, guarantees each guest a tailor-made care service.

A multidisciplinary team guarantees personalized and complete assistance both for the use of internationally validated rating scales as well as all the information collected by the various services.

The objective of this program is the enhancement of the individuality of the guest who is evaluated in its complexity, building around him, and not vice versa, the support activities and allowing, thanks to the multiplicity of interventions of every moment of the day.

2. To continuously monitor the situation, evaluate the results of the activities/tasks implemented and, if necessary, make any changes to the intervention plan and/or to adapt the activities to the new situations that have emerged in the meantime.]

Since February 2020, due to COVID restriction, face to face weekly meetings are suspended and caregivers must substitute *équipe* meetings with online meetings, emails communication or WhatsApp group/call.

With the impossibility of any kind of contact with the extern, also visits have been suppressed and the involvement of the familiar, that is fundamental in decision making process in a situation of dependent people is changed: the process of communication is now managed by the coordinator who takes decision with other professional and familiar using “indirect” communication channels (i.e. calls, messages) and so represents the point of reference and information for all actors involved in care relations. This process isn't formally regulated, but everyone refers to the coordinator in the way he/she prefers and after the coordinator manages information flow and shares it to all the others.



In a normal situation the family plays a crucial role in the decision-making process: they are the main source of information at the beginning of the care path - we have patient not able to communicate reliable clinical situation nor personal information -; familiar are constantly updated and consulted before any decision or change; they are the one taking the final decision for their parents. Generally, families are in charge of entering their parents in the residential structure, accompanying and supporting them, with the cooperation of the general practitioner, during the process. They have to explain to their parents about any steps and about what's going to happen to them with simplicity, clarity and honesty. The access in care services is managed by Italian National Health System (SSN) and it's regulated by National Law. The procedures are quite complex for end users so they are managed by familiars and general practitioners.

To summarize, the COVID emergency has changed a lot the relation of care, increasing problems and challenges such as lack of time, the isolation from the outside, the difficulty of systematize and apply a real integrated user centred approach. The communication, in all its three aspects (between caregivers and 1. other operators; 2. care receivers and 3. familiars) represents one of the main tool and channel to guarantee the best care service and to improve quality of work (for the caregivers) and quality of life (for the care receivers).



Spain

Case study 1: Promotion of autonomy

First of all, this service is for people with physical disabilities such as spinal cord injury or amputations. Promotion of autonomy provides all their participants with tools to conquer their independent life projects. The main principles of this service are based on a person-centered model. These are people's dignity, their self-determination, their independence, avoiding overprotection and deinstitutionalization. For organizations to create a good relationship between professionals and users, professionals with magnificent social abilities are selected. One of the most important verbs we use is "to agree on". From the beginning we research the specific interests of the person. Sometimes they collide with the professional's point of view, so it is important to reach an agreement.

The team is composed of psychologists, neuropsychologists, speech therapists, social workers, nurse assistants, occupational therapists and physical therapists. Every and each professional is important and gives information to the rest. The team is managed by a coordinator. When it comes to making decisions, it is the whole team that participates. There is also a department which is focused on community participation. From this area they try to include people with disabilities into the rest of society, not just groups of people with other disabilities. Each professional must pay attention to what resources are needed as well as what other professionals are doing.

At the beginning, a social worker goes to the person's home and makes an initial assessment. After that, there's a meeting where the social worker introduces the person to the rest of the team (Our team is composed of 7 areas). According to what is said in the meeting, one expert or other will continue intervening. This process is repeated by each area until one professional from each area has visited the person. Everything is registered thanks to an IT system.

We make follow-up meetings frequently and periodically, so everybody is updated and knows what must be known about each case. When someone presents a different necessity than usual, the social worker is always consulted. We coordinate ourselves, so we can meet that necessity or find external resources which can. To apply the principles of inclusivity, it is very important to make them feel as



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an indispensable part of society. In order to reach that goal, professionals should always include them into groups. It allows the person to see that they are not as different as they think. There is too much disinformation, when people begin a life with a disability, they feel overwhelmed. A person who accompanies them during the whole process and informs them of everything is needed.

When there's challenging communication, it is needed for a positive and accessible language. It means it is not full of technicalities. It is important to be assertive, everything can have a positive outcome if you use the appropriate tone and words. It is also important to have evidence of what you want to prove. The language these professionals use is a caring one, very humane and warm. It is also important to propose short-term goals, which are more easily understood. Moreover, they should never be forced to accept anything. One good example of difficult communication is when you have to advise a family member to incapacitate his or her relative. In this case, the concept is always explained making sure family members know it is beneficial and avoiding a feeling of guilt. Incapacitating someone sounds really aggressive, so it is better to tell them that they are going to protect him or her.

Obstacles faced by this service are several. Short time and small budgets are the most limiting ones. Other obstacles are pressure from professionals or indecision from users. This lack of time can have terrible consequences, coordination or quality service can be affected. For this reason, it is crucial to manage time and resources as effectively as possible.

In conclusion, this service is based on a person-centered model. Their professionals focus on an interdisciplinary approach which takes into account their user's desires. Professionals must bear in mind that it is common to see dependent relationships between caregiver and people with disabilities. Providing an empowering service, instead of meeting all their needs. People with disabilities are not just receptors of services, they can create resources for the community. For this service to be effective, we must break this dependence in order for them to be autonomous.



Case study 2: Accompaniment

It is a personal support service that allows the person to enjoy the highest level of autonomy in the development of their life project and facilitate the exercise of self-determination. This support is intended to carry out the basic activities of daily living or to collaborate in the development of other activities to promote personal autonomy, encourage independent living and facilitate access to education and work.

In this service it is the disabled person who decides when, how and in which activities he or she will use this support, therefore, the service must be adapted to the changing needs of support and prioritize the freedom to decide and the independence of the person. We take into account the priorities of people we attend to. In our service, we create a plan. Before the creation of this plan, a professional arranges a meeting with the person and assesses what necessities he or she has. After that the plan is written. This plan includes instructions created by professionals but always taking into account what the user has demanded.

The most important principle is self-determination. For us, it is crucial to help our users to create their independent lifestyle project. Taking this into account, we're going to provide them with the necessary tools to reach that goal. One of these are personal assistants. The main job of personal assistants is to help people with disabilities in their daily activities which do not involve caring. For example, in their job or in their free time.

One big obstacle is the way people with disabilities are handled. It is usually believed that basic needs are the only one which have to be met. They are important, of course, but there are also a lot of other aspects which are essential for everyone to have a meaningful life. It is not just working with them; it is also knowing how their environment affects them and their current state. When necessary, we involve their family in the decision-making process, they participate in the creation of their individual plan for an independent life.



A difficult communication could be to inform someone that we can no longer provide a service. We would make use of positive language. We will never leave him or her alone, we will find another kind of help. It happens frequently that the person who receives the services demands more than what is possible. In this kind of situation, we explain to them assertively why their demands cannot be met. Bearing in mind the necessities and desires of the people we attend is not the same as meeting all their needs. For this reason, it is also important to set some limits.

The collective we attend to is completely dependent on the personal assistant. One barrier they have is the following. If there is the possibility to enjoy the service of a personal assistant, the time is very limited. This person should be available for almost everything. For instance, if a person with a disability needs to go to work or if they just want to go out with friends. They aren't just for productive time; they are also needed for free time. Or maybe there should be more than one personal assistant for each person so we can prevent burn-out syndrome.



Poland

Case study 1: Social Welfare Home for the elderly on the example of the Helców Social Welfare Homes in Krakow

This case study presents the method of organizing and conducting childcare practices for people requiring round-the-clock care due to age, illness and / or disability, based on the example of the Helców Social Welfare Home in Krakow (the SWH), which has existed since 1890. It is a public unit of the Municipality of Krakow operating in the field of social assistance. Currently, the SWH consists of 5 facilities with a total usable area of 19,873.10 m², including one building with an auxiliary function (kitchen and laundry) and 4 facilities with 12 nursing and care teams (1 male, 4 female and 7 mixed). The SWH has 387 places for chronically somatically ill people, for whom it provides 24-hour care (currently, out of 387 seats, 350 are occupied).

The scope of services provided by the SWH for residents is adjusted to their physical and mental fitness. As part of these services, the SWH provides assistance in basic life and care activities, as well as in personal matters and meals. Residents of the SWH can obtain support and psychological advice. The SWH provides residents with physical rehabilitation, including bedside rehabilitation, as part of individual therapeutic rehabilitation programs. Residents of the House have the opportunity to use the library and various forms of therapy like for example music therapy and interest groups like artistic handicraft workshops, an art studio, a chess corner and logic games, a press corner, a culinary corner, a movie club, etc.

The Social Welfare Home provides a wide range of care services for its residents, i.e. nursing, hygienic and medical treatments (prescribed by a doctor), administering medications, therapeutic, psychological and social support, support in family relationships (with family members of the residents) as well as a spiritual care.

The residents of the SWH are people from very different backgrounds, with very different life experience and social status. The reasons why they live in the SWH are very different and their life experiences are extremely varied. As a result, their expectations regarding care services and other



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services the SWH offers are very different and individualized. With such a wide variety, the strategy and practices used by a professional's team of the SWH looking after the residents of the SWH are the sum of observations, experience and also the applicable law (related to the care services that such Social Welfare Home can provide to their residents).

The procedure for admitting and residing a person to the SWH follows the following steps:

Establishing contact with the resident or his informal caregiver (e.g. family member) before living at SWH, i.e. after receiving the decision on admission to the SWH and agreeing the date of residence.

The introducing and adapting process of the resident. These are the first days of resident staying in the SWH. For new residents, the first days at the SWH are very stressful because they change their place of residence totally. At the beginning of this stage (first day) to getting know the new resident a social worker, a representative of the nursing and care team are involved. In the following days a psychologist and a therapist are involved too. It is important to build the relationship between a resident and the SWH staff.

The first days of the resident's stay at the SWH is the time for the assessment of independence on the Barthel scale and the assessment of his/her mental fitness. The assessment is carried out by the nurse from the nursing and care team. Depending on the physical and mental state of the resident, a care team is selected as well as the resident's environment, i.e. the room in which he/she will live (e.g. if a person in a wheelchair, appropriate space to move around, choice of a roommate by age, etc.). The stage of getting know the resident with the SWH is a very individual path (although it is carried out in accordance with the procedure), it includes a nursing diagnosis, which serves to develop an Individual Nursing and Care Plan, but also to learn about the residents' daily practices, customs, individual physical and spiritual needs.

Admitting residents to the SWH is accompanied by a lot of stress (because they say goodbye to their current life and changes the environment and place of residence), so it requires delicacy. There is a procedure with elements that should be included in this process of admitting a resident, but it is more



important that the new resident of the Social Welfare Home feel comfortable and see that someone is interested in him/her. The above-mentioned procedure for admitting the resident to the SWH shows that **the strategy of caring for the residents of the SWH is based on relational work: resident - staff. All activities towards the resident are coordinated and oriented towards their individual needs.**

From the very beginning, the residents of the SWH are looked after by a team consisting of specialists with various disciplines (multidisciplinary teams). The diagnosis and definition of the Individual Nursing and Care Plan, which is prepared by nurses in cooperation with the doctor play the main role in the selection of the staff team to the resident's needs. The social worker and psychologist have constant contact with the residents. They give a signal regarding the further care services for the residents. The care services are done by a team of specialists, which includes: a social worker, a psychologist, a nurse, a doctor, a physiotherapist, and other specialists, depending on the psychophysical situation of the resident (e.g. the SWH cooperates with the psychiatry of the Clinical University).

The residents are involved in establishing the Individual Nursing and Care Plan, in particular in part of the various supporting activities (like for example: rehabilitation, therapy, workshops, interest groups, etc.). There is a dialogue with the resident in terms of his needs, expectations and planned achievements. This process of a person's participation in the planning of their activities is permanently ongoing. Communication - the way in which the SWH staff addresses the residents - this is one of the basic programs of the SWH. The staff does not use the word "a client/customer", but "a Resident", "a Person". An important element of care is the approach, which means "*Participating in the process of organizing help for the resident. We - the staff are not experts on the life of the resident, because He / She has his / her own life experience. It is the resident - the person we look after will admit us to the extent that she wants to*"

The most important values that the DPS staff share in providing care are:

- Respect for human dignity - in each person we see a person who requires respect
- Showing concern and interest



- Providing a sense of security so that you do not feel threatened to live
- Maximizing our commitment to his life. Our concern does not stem from regulations, but is genuinely at the centre of our concern. “We do not want to replace the family, but we want to be friends with him”;
- Using his (inhabitant's) potential for his activity

Diagnosis, identification of needs, and an individual support plan are the most important elements of the care process for the SWH residents. These documents are prepared from the perspective of various specialists and various fields, based on the identified needs and capabilities of the person - resident. The family and informal caregiver of the residents participate in certain processes, as much as they wish or can. If it is possible to get to know the resident, his priorities and habits through contact with the family, it is done. But it is not always possible, e.g. the family lives far away, or minimizes the contact with the resident, they are not interested in. Very often the SWH is an advocate for residents in various matters, it also happens that it is also an advocate for the family - e.g. if a resident is in conflict with the family (e.g. inheritance, debts, etc.).

The Diagnose that identify the resident’s need, and **the Individual Nursing and Care Plan** are the most important elements of the care process for the SWH residents. These documents are prepared from the perspective of various specialists and various fields, based on the identified needs and capabilities of the resident. The family members and/or informal caregiver of the resident participate in certain processes, as much as they wish or can. It is important for the SWH staff to get to know the resident, his priorities and habits through contact with the family. But it is not always possible, e.g. the family lives far away, or minimizes the contact with the resident, they are not interested in. Very often the SWH is an advocate for the residents in various matters, it also happens that it is also an advocate for the family - e.g. if a resident is in conflict with the family (e.g. inheritance, debts, etc.).

The SWH team uses various tools in the monitoring and evaluation process of taking care of residents. First of all, it includes:



- *Daily Nurse Reports* - these are reports by nurses at the end of each day and night. Report includes situations and observations that are important to the staff who are caring for them. The superiors will also read these reports.
- *Social work cards* - kept by social workers
- *-Therapists' work sheets* - conducted by therapists
- *-Psychologist work cards* - conducted by psychologists

On the basis of the above documents, monthly reports are prepared collecting information from all members of the caring team. Monthly reports are the basis for the entire team to discuss the Individual Nursing and Care Plan and its modifications. The manager approves the plan and its modifications. At the next meeting, the verification of what has been achieved is carried out. The DPS director performs ad hoc controls.

In summary, the DPS home care program is conducted in accordance with the "person-centered care" approach, which is understood as coordinated activities focused on the needs of the resident of the SWH. Care and support for people living at SWH is based on relational work, where the most important is the relationship: resident – the SWH employee. The action and support plan depends on the elderly person. It is not easy, because the residents of this SWH come from very different social backgrounds, have very different life and professional experiences, and sometimes it is difficult to reconcile their expectations and needs. The DPS staff tries to do it as far as they have resources and means.



Case study 2: The Daily Support Center in Gorlice, run by a non-public entity - the Association on the Family Assistance "Hope" in Biecz

The case study presents the practice in the field of care for dependent people, provided by the Daily Support Center in Gorlice, which is run by a non-public entity - the Association on the Family Assistance "Hope" in Biecz (the DSC Centre), that was established in October 2003 and operates on the basis of the Regulation of the Minister of Labor and Social Policy of 9 December 2010, as amended on social self-help houses - type A, B. This is a facility of daily-stay social assistance with a local range. It covers the area of the Gorlice Poviast (south of Malopolska Region).

The DSC Centre is intended for people who, due to mental crises or intellectual disability, have serious difficulties in maintaining their social integration, and especially in fulfilling the roles of everyday life, their relations with the environment, education process, employment, matters related to the material foundations of existence, etc.

After the initial assessment of the person's situation, an Individual Supporting and Action Plan is developed and implemented. The participant of the DSC Centre (dependent person) is actively involved in the implementation of this plan. The plan is adapted to the needs and psychophysical abilities of the participant. The realization of the plan is coordinated by the attending assistant. According to the framework plan, therapy classes in individual laboratories are organized throughout the week from 7.30 am to 4.30 pm. Each participant of the DSC Centre admitted to therapy can use this proposed form of therapy during the day according to their talents, possibilities and interests. In addition to classes in the studios - the participants are required to choose group therapy.

According to Polish law, the DSC Centre activity is subject to social assistance (social policy), not health care (health policy). The activity of the DSC Centre is most similar to that of day psychiatric wards. The DSC Centre is focused on people who are chronically mentally ill. Every year, the centre prepares an action plan, which is submitted for approval to the Social Policy Department of the Voivodship Office (which finances the DSC Centre's activities).



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In general, the action and support plan for DSC Centre's participants is based on the approach (method) so-called "the therapeutic community", i.e. it is based on two main principles: (1) community and (2) democratic resolution of common issues. It consists in the fact that all participants of the DSC Centre are divided into 3 groups - the so-called small communities that meet twice a week. A therapist is assigned to each group. All groups (these small communities) will meet together once a week with the DSC Centre staff (specialists and support staff). At these meetings, both small communities and all groups together, various topics are discussed: what happened, interpersonal relations, formal issues, and plans are made for the next period. Each group has its own chairperson, chosen from among the participants, who reports back. It is the main tool used in working with participants and for socializing.

The other tool that the DSC Centre has been using for years is supervision. Supervision of work that is run based on the therapeutic community method is conducted by a supervisor, who is a psychiatrist and psychotherapist working in one of the hospitals in Krakow (in the hospital ward on personality disorders and neuroses). During the supervision, various situations, events and problems that occurred in the groups (these small communities) are discussed, which helps a lot in further work. The therapeutic community and the supervision are the two main tools (that the DSC Centre staff use to work with participants. In addition, the support program for the Centre's participants includes various activities, trips, etc.

The participation in the DSC Centre is not limited in time. All this is individualized, depending on the psychophysical situation of the participants. The DSC Centre has participants who have been participating for several years. Each mentee has an individual therapist. They both meet together once a week (on the same day and at the same time), where they discuss the mentee's needs and plans.

During individual and group meetings, the daily matters of the participant are discussed, the staff team want to reflect the participant's life outside, what kind of problems they have on the outside. Support for the participants also aims to prepare them to be better connected with the community, but also in terms of self-empowerment and socialization. The DSC Centre tries to prepare the participants for professional activity, but it is not about working on the labour market, but becoming independent,



which means that, for example, a participant can go to an office on his own and deal with an issue, or go to a doctor. The DSC Centre team is comprised by professionals from different disciplines, that is psychologist, therapists, psychotherapist, physical therapists. The centre cooperates with social workers, healthcare staff (doctors) but this is mostly informal relation.

The DSC Centre runs a special cooperation program for the families and caregivers of participants using the support. The program consists in organizing a weekly support group for family members with two specialists (therapist, psychologist) where various problems and situations that occur in the home or environment are discussed. There are also duty hours (stationary and by phone) for families.

The DSC Centre team uses various tools in the monitoring and evaluation of the supporting process. First of all, it includes: *weekly meetings* of the team and *half a year meeting* when the action plan is verified and modified.

In summary, the Centre supporting program is conducted in accordance with the "person-centered care" approach. The uses different tools that coordinate activities focused on the needs of the participants.



Section 4: Conclusions

The present report is the outcome of the fieldwork conducted in all partner countries. The results are ten successful case studies of person centred care. From the information collected it is evident that the strategies implemented in all five countries have some common ground. Specifically, the following themes emerged from the analyses of the fieldwork results:

- Care practices followed by the organisation,
- Cooperation and coordination of multidisciplinary teams,
- Communication and use of person-centred language,
- Involvement of the person and their family in the decision making process,
- Inclusivity and accessibility of care services for dependent people,
- Monitoring and evaluation tools for care services,
- Barriers and solutions to problems in person-centred care

The organisations that were the focus of all the case studies do not follow a specific model of care that is universal throughout. However, in all partner countries the care organisations follow specific protocols when providing their services and have a lot of similarities. The main similarity involves offering individualized care to each person. The care professionals described the care practices of the organizations as being person centered and holistic. It is evident that the main values of the care organisations focus on empathy and respect.

When creating a care plan for service users' individual differences are always taken into account and respected. Most of the care professionals focus on empowering their service users to help them maintain their independence for as long as possible and avoid institutionalization. It is apparent that part of the care practices of the organisations is integrating of the dependent person in the community and promoting autonomy and advocating for the rights of their service users.



During the creation of a care plan and the decision-making process, the dependent person as well as their family are involved in order to ensure that their needs are being taken into consideration and that any decision they make regarding their care is respected. The persons and their families, in collaboration with the care professionals, are the ones who make the final informed decisions about the services and the type of care they will be provided with.

In all partner countries the organisations studied, stressed the importance of teamwork. The teams are made up of multidisciplinary professionals who work together to make decisions about the diagnosis of the users when diagnostic procedures take place as well as to create the individualised care plans. Regarding the exchange of information among coworkers within the organisations, in most partner countries the protocol was similar. The team members share information about the users and the daily activities of the organisation via an online database. In order to ensure a good cohesion among the multidisciplinary teams, in all partner countries the care organisations that were studied had similar strategies. In all organisations supervision had a significant role in the cooperation of the multidisciplinary teams. In most organisations the supervisor held regular meetings with the team in order to discuss any problems or concerns as well as the progress of the care plans of the service users.

The professionals that were part of the organisation countries studied were aware of the importance of communication. When communicating with service users the care professionals always try to maintain their empathy by using person centred language. This means that they try to avoid using negatively-charged words (eg. patients) when talking to dependent people. Instead, they use positive language that takes into account the person as a whole and does not focus on their disability and dehumanise them. Furthermore, while working with dependent people most care professionals reported being mindful of how they interact with them. In the majority of the organisations studied, the professionals try to encourage effective communication with the service users by trying to use simple language while explaining their care plan, as well as trying using non-verbal communication as a way to help service users who have difficulties in speaking and understanding.



Finally, it is important to point out the obstacles and challenges care professionals reported to face when providing person-centred care. The lack of adequate human and financial resources as well as the limited time available, have been reported to hinder their endeavors to provide person centred care. Currently, the care professionals report to have added pressure on their work due to the pandemic. All the above will be taken into account and lead the process of the design of the IntegraCare training programme.



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Appendix

Fieldwork results Greece

IntegraCare: Person-centred care training program for multidisciplinary professionals

Phase 1

Fieldwork Results

Athens Association of Alzheimer's Disease and Related Disorders

(AAADR)

March 2021



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Theme 1: Care practices followed by the organization:

Relevant Quotes

« . . .equality on the relationship between the therapist and the person, authenticity, honesty and sometimes self-revelation. . . (it is important) to have frequent contact... something that prerequisites good boundaries. . .I include these notions (advocacy & empowerment) in my practice . . . For people living with dementia and their caregivers I provide advice and instructions on the importance of maintaining a sense of autonomy . . . to enhance their sense of dignity . . . let the person make some chores. . . the person will have the sense that contributes and is a useful member of the family. . . In order to cooperate with the person facing the problem. . . I have to build a relationship with them so that they can trust me. . . I always ask the persons consent to share information with other professionals” **Psychiatrist, Home Care setting**

“We work as a team to provide care. . . (our values are) definitely “the caring” . . . providing meaningful care, knowing that the persons are satisfied with our services. . . and our work has a meaning. . . The social worker and the doctor collect information and evaluate the needs so as to allocate the cases properly to each professional. . .When I get a referral I see their record and their request. . . In my first visit I explore what is that they need. . . I ask them questions to confirm the request. . . I observe. . .I think I create a sense of familiarity in the homes I go, this is good for me too as they can trust me. . . ask me more comfortably what they need. . . so I can understand more quickly their needs. I create an optimistic atmosphere. . .When (due to the nature of the problem) we are not able to work with them, we refer them to another service through our social worker”. **Nurse, Home Care setting**

“The first step for the person is to take a “memory test” and get examined by the neurologist...if the person is referred to us from another doctor, we look at their referral... The social worker does the history taking which is essential in order to obtain information about the personal characteristics, the living environment, they profession they practiced, things they liked in the past and the present...” **Psychologist, Day Care Centre setting**



*“Many times, we find alternative ways...Someone that is not receptive to getting our services... you take their interests into consideration... you take their personal characteristics into consideration so as to customize accordingly your intervention plan” **Social Worker, Day Care Centre setting***

*“The aim is to help people with dementia and their caregivers...4 out of 5 days I go to houses, we help people with their hygiene, we help them walk, take care of their wounds and other nursing related issues...we give advice regarding feeding...we also help with the psychological issues of the caregivers because they are isolated and are usually happy to see us...Our values are that all people should be provided with care...even for the one day we try to offer as much as we can to each person” **Nurse, Home care setting***

*“There is the neuropsychological assessment, the first step, then there is the neurological examination, then (we) offer cognitive training, pre-Covid in groups, now online or on phone whatever we can do...and there is support for caregivers...the values of our organisation are empathy regarding the problems of the service users and their caregiver...covering all of their needs as a whole in one setting is very important so that the caregiver doesn't have to go somewhere for a doctor and somewhere else for a psychologist etc...The psychological support we provide to caregivers is person-centred...we have regular contact with each individual user” **Neuropsychologist, Scientific Supervisor, Day Care Centre***

*“Individualised care, holistic approach, recognising the needs of people with dementia and their caregivers, as well as cooperation with the service users in order for our services to be adapted and cover their needs...For example when a person wants to visit the memory clinic to have an assessment, they are informed about all the potential ways this process can be done, according to where they live, their mobility...Information is provided and counselling to each caregiver individually...Also referrals to other organisations and services that are most appropriate for covering their needs...(our values are) Responsibility regarding service provision, kindness, respect of the dignity and uniqueness of each person with dementia and their caregivers, as well as respecting and ensuring their rights, maintaining confidentiality, getting informed consent before any action” **Social Worker, Day Care Centre***



Theme 2: Cooperation and coordination of multidisciplinary teams

Relevant Quotes

«When a person is referred to me- usually by a psychologist...after my evaluation I make sure to inform them (the psychologist) always provided that I have the person's permission... When collaborating with professionals from different disciplines we exchange information, discuss, share our thoughts and get advice from each other. There are distinct boundaries for the extent of knowledge all of us have. . . which makes us more receptive to each other's knowledge.

... I do not only contact my colleagues when I need them”. **Psychiatrist, Home Care setting**

To begin with, we work as a team in order to provide care to each person. . . We start as a team and then we allocate each case to the professional or team of professionals needed. . . There is a database which I will access and read the records. . . everyone keeps a record in this database. . . I can read what my colleagues have done. The social worker records there all the requests based on the professionals they need. If I see that a person needs psychological support or. . .I refer them to the psychologist. . .to the physical therapist. . . Every Monday we have a team meeting. . .we discuss the current issues and make a plan. . .There is the sense that we are a team. . .The fact that the organization is supportive towards the employees, willing to listen and discuss is itself helpful (to maintain a positive and productive relationship between professionals) . . . you know which is the person you can refer to when needed. . .everything is organized and this is good” **Nurse, Home Care setting**

“As healthcare professionals we always or mostly work multidisciplinary...Keeping a good collaboration depends also from your personality and your intention not to overstep on their field of expertise. **Social Worker, Day Care Centre setting**

“By prioritizing the beneficiaries and understanding that this job cannot be done by one person... It takes a team of people and each professional has his own role in this care... By understanding the value of each professional in this collective effort; understanding that we cannot function unless working with each other....” **Neurologist, Day Care Centre setting**



“ At Friday’s group meeting we gather the neuropsychological evaluation, the neurological examination, the information from the history taking and we assign them to the team that we think will work best for them. The neurologist, who has a well-rounded view (of the person’s state), makes suggestions and then the whole team co-decides... There is a common excel drive where we all write what has happened so whoever (of us) sees it can be informed... We also have a group chat on viber but this mostly for our personal use not for the beneficiaries... We meet and communicate with each other very often... It is important for our team that each one considers the needs of the other in the provision of care... We share time together on our lunch”. **Neuropsychologist, Day Care Centre setting**

“(When there is an issue) We will refer it to the team coordinator in order to solve it and there will be communication among the professionals... The boundaries are set both from the coordinators and the professionals”. **Physical therapist, Day Care Centre setting**

“It is important that the problems that arise are discussed. Every Friday we sat together and discuss the issues we had during the week... It is important to be aware of your duties and your limits...”. **Nurse, Day Care Centre setting**

“(After each healthcare professional collects information for the person) All the professionals gather together... to evaluate how can each on of us from their side can contribute to the care... depending on what the person needs” **Psychologist, Day Care Centre setting**

“In the mornings we have some time and we talk about issues...once a week we have a meeting and we discuss things that concern us...For the home care service we have a meeting on Monday morning where we talk with the social worker who assigns our appointments...we talk about our questions or fears we have, if we need help...After each appointment we write in an excel file which is like a journal what we have done...therefore we have a database where (the others) can go on and see what I have done at each time each day...We try to go out together as colleagues...this helps us bond...I think that the association hires people who have a personality that would not create problems...they are cooperative” **Nurse, Home Care setting**



“We have an excel file if something has to be told to a colleague we write who it is from in a comment and to who it refers to and the date...so all members of staff have to open the file to see if there is anything (for them)...It is true that when you work in a setting like this and you have a lot of users...sometimes you get tired, the space doesn't help...there might be some tension...I believe that staff meetings are very important to not only discuss what to do for each user but what are your concerns or complaints regarding your work...it helps bonding with each other...we also try to eat (lunch) together so we can bond...In these meetings I believe that everyone should participate and should be listened to and each person should have the time and space to talk about their struggles...we show each person that they are heard and we want to make things better...and that they are not just a machine here to work and we don't provide you with any support...The organization understands how psychologically tired health care professionals are...any time I need to I can pick up the phone when I am dealing with an issue and talk to someone who might solve it...”
Neuropsychologist, Scientific Supervisor, Day Care Centre

“Cooperation and exchange of information is necessary for the smooth functioning of our organization and the high quality of services...There are databases where each day the information regarding each user is written...there are also daily journals that include the type of interventions that are provided, who participates, different comments...Each week there is a staff meeting where different issues are discussed...On a monthly basis there are meetings with an external supervisor where different solutions are given to problems...Moreover, to increase team building we organize different activities like trips, meals, exercise groups”
Social Worker, Day Care Centre

Theme 3: Communication: use of person-centred language, attention to non-verbal communication

Relevant Quotes

“I refer to them with their name. I do not use any definition that refers to their capacity. . . I implement arts in my practice to a large extent. . . I make sure that the person feels like they have a saying in what is discussed about them. . . I address them even if they are not able to speak and I make eye contact. . . My endeavor is not to behave like the person does not exist. . . For example, a woman. . .



was not able to speak but she was able to understand, if you provided choices or visualized the questions, she was able to express herself”. **Psychiatrist, Home Care setting**

“I always rely on the fact that they have an understanding at least to an extent. . . When I shower them, I always watch their body. . . notice if there are any signs and try to evaluate them. . . for example there could be signs of abuse. . . I watch, I ask the caregiver about their state during the week and mostly by watching the person and their moves. . . **Nurse, Home Care setting**

“ We say beneficiary... person with dementia” **Social Worker, Day Care Centre setting**

“... When a person hears the word patient, they can feel inferior or that we insult them... we should not marginalize them. **Neurologist, Day Care Centre setting**

“ (The use of positive language) helps in the elimination of stigma, in building a culture.. In addition, when characterizing some with the name of their condition...I feel that the person is objectified and it is as if this person is charged with all the symptoms of dementia... For example, for someone that has difficulties in speech...a good approach is to listen to them carefully, try to paraphrase their words so as to show them we understand them or give them some words so as to continue (talking)... (This way) we want the person to feel good, feel that they participated in the conversation and communicated with us. It is kind of the same also for aggressiveness; if we keep our voice volume low, talk slowly and clearly... smile and have a calm expression... talking about a topic they like so as to unload the tension”. **Psychologist, Day Care Centre setting**

“The language (we use) is important for everyone not just the person... The way you welcome someone in the place is also very important, you will welcome them kindly... I personally think that we should not treat them differently as someone who came here because they have a specific issue; we treat the same way as everyone else”. **Nurse, Day Care Centre setting**



*“And the use of incentives (is important); incentives have a effective role in the communication with the healthcare professional... For example, if someone’s behavior is turbulent, you can calm them using an incentive. You can take them to another room and give them something else to engage to... as they shift their attention to something else... We always talk kindly, in the first person in order to make them feel familiar with us... we approach in a friendly way” **Physical Therapist, Day Care Centre setting***

*“ Eye contact and touch are also important...Because when all the senses decline these remain, even to the final stages of the disease... I remember Panagiotis who was uneasy and we knew his job was to manufacture buildings; we showed him a video about building a skyscraper and all of a sudden he calmed down... it was familiar for him but we had to know his story for this” **Neuropsychologist, Day Care Centre setting***

*“To people with dementia we try to talk as simply as possible...they open up to us...we try to create a friendly climate in order to be able to communicate because they (people with dementia) have problems with communication especially in the later stages...we sing to them sometimes, make jokes, humour plays a big role in the communication with the person...We are smiley and pleasant as much as we can, we sing to make them feel better, singing helps a lot because it is one of the last things to be forgotten by a person with dementia...we try to be as expressive as we can...we speak loudly and clearly” **Nurse, Home Care setting***

“Yes I have heard of it (positive language)...I refer to them (the person I provide service to) as a person with cognitive difficulties as someone who has a certain condition (dementia) I don’s say for example they are schizophrenic I say they are a person with schizophrenia...It is important...if you say they are schizophrenic you are defining them, they stop being a person and become a disease, if you say they are a person with schizophrenia you show them that you first see them as a person and then you see the disease...it shows respect”

“We explain (the findings of assessments) to them very simply, we encourage them a lot...I try to relax them as much as possible and try to make it (assessment) seem like a game and at the end I



*explain to them that there are some issues...I don't lie to them but I speak very simply...When a person cannot communicate I give him enough time...I try to understand...I repeat things to see if that is what he wants to tell me...I take my time...at the centre I work in we offer art therapy...the therapist lets them express themselves by drawing, to express themselves through a way that is not verbal communication...I have noticed it helps...We have a questionnaire that we have made for these cases...we ask questions based on our experience here based on the things that we need to know with yes/no answers..." **Neuropsychologist, Scientific Supervisor, Day Care Centre***

*"Referring to the service users of our organisation the terms all professionals use are "people that deal with problems in their cognitive functions", "people with memory problems", "people with dementia"...We avoid terms that are emotionally charged that might make the users uncomfortable or even offend them like patients, disability, disease...Understanding, respect, acceptance, empathy and active listening, these are the values I try to rely on when building a relationship based on trust with a person...communication is important so they can express their concerns and fears...Through conversation people are encouraged to talk about themselves, their life story, their interests, the difficulties they face, to understand and express their needs and issues...(If verbal communication is not possible) Through non-verbal communication, observation of their body language, I use pictures and touch as well as eye contact...Oftentimes a service user from a group has difficulties expressing a need, hunger, tiredness, using the bathroom, in this case I have tried to calm them down and tried to show them either verbally or non-verbally the different options we have to cover their need while observing their reactions" **Social Worker, Day Care centre***

Theme 4: Involvement of the person the family and the informal caregivers

Relevant Quotes

" I collect the information-except from rare cases- from the patient. If the person is not able to communicate, I collect the information from a reliable caregiver. . . The rule is that the person that I provide care to, will make the decision. . . The strategy I follow is the participatory decision making after informed consent. Meaning that I will inform my patient about the available choices, the pros and cons of each choice . . . and we come to a decision together. . . I will clarify my recommendation



*and then it is their choice and decision to make. . . If I see that the person is not capable of making the decisions and handling the instructions I provide, then the primary caregiver will take responsibility. . . Cooperating with the caregivers can have both a positive and a negative impact. For example, I had a situation where the primary caregiver communicated to me a very different picture- maybe so as to gain some secondary benefits- and then when I saw the patient my evaluation was completely the opposite” **Psychiatrist, Home Care setting***

*“ A family member makes the request for our services and is the person we make the first contact with in order to obtain some basic information prior the visit. . .In my practice I include both the person and the family/caregiver in the decision making. . . I guide them. . . I work with the instructions of the doctor which I explain to them. . . I will discuss it with the caregivers. . . Every professional should have the ability to set their boundaries. . .” **Nurse, Home Care setting***

*“..We interview both the person that is being examined and the person accompanying them which most of the time is someone that knows the person well and knows their habits, their interests, their abilities... Personally I explain to them all the options they have. For example a medicine can be taken in the form of a pill or in the form of a sticker; in this situation it is important that they make the decision because it depends on the person’s lifestyle. We are going to make a different plan for someone living alone and someone that has always someone else with them... We discuss both with the person and the caregiver. I provide alternative options and then we discuss it and find the option that works and fits best to the person...” **Neurologist, Day Care Centre setting***

*“Sometimes we ask more actively the participation of the caregivers “Tell us how was the team for them?” we get feedback. We do not do it for everyone because of the big number of people participating... some (caregivers) tend to intervene...If someone does not want to participate in the teams or do the “memory test” we give the right to do so... I personally believe that those involved in the provision of care, the caregivers that are motivated and build a good relationship both with the persons and us, I feel that (the beneficiaries) are overall doing better”. **Neuropsychologist, Day Care Centre setting***



*“It is a fundamental principle not to put pressure on the people”. **Social Worker, Day Care Centre setting***

*“When we go to a new appointment we always see the person with their caregiver, the information we get is always from the caregiver...after we speak with the caregiver we talk to the person we are caring for...we tell him simple things like who we are and what we are doing there...cooperating with the person themselves helps me...but cooperating with the family (helps) too so they can be more calm...often in the first appointment the caregivers are very stressed...we try to show them how to do things so they are not so at loss...it is important to have peace...An example of this is: we went for the first time to a person with dementia who was bed ridden and his wife was also older...the other nurse went to speak to her and I went to see him...at first he was a bit uneasy but I started talking to him and he calmed down...I started to take him to the bathroom alone...it was fine...then his wife came and she became anxious...as a result of seeing this stress he became more upset and started asking for her...when we explained to her what to do and how to work together with us we stopped having as many problems” **Nurse, Home Care setting***

*“Usually for the people that need care...after we see the person themselves we ask the caregivers question...for the safety of the users we need to keep their families informed...we ask who the caregiver is so we can understand if they have a good intention...we have a lot of documents...to be sure that the person that is there is their caregiver and does not want to take advantage of a situation” **Neuropsychologist, Scientific Supervisor Day care setting***

*“During decision making regarding a person’s care plan the person themselves takes part as much as their cognitive state allows them, this should be encouraged and supported (by professionals) and their personality, way of life, values and rights should be taken into account...Their family members that take care of them should also be informed about the care services provided and their own position and needs should be taken into account in the decision making process...this (involving the family) is undoubtedly helpful and even necessary I would say, because this is the only way an appropriate care plan can be organized and applied, based on the individual differences, needs, abilities and general way of life of the members involved” **Social Worker, Day Care Setting***



Theme 5: Inclusivity and accessibility of care services for dependent people

Relevant Quotes

“If someone has difficulties in transportation either due to problems in movement either. . . I will make a home visit or now use the technology of telemedicine”. **Psychiatrist, Home Care setting**

“I will go to everyone (that makes a request)...then we evaluate where we are most needed. . . I provide everyone with instructions and let them know that they can reach out to me when they need help. . . I do not exclude anyone. . . Our services are free of charge”. **Nurse, Home Care setting**

“We make face to face visits, (we communicate) by phone, online and by email...There should be a redistribution... If someone calls at the day centre of Pagrati and there is a waiting list, they are referred to the day centre of Marousi where the waiting list is smaller...This requires a communication between the day centres which is what we do; this could be applied in a broader context. It could be very helpful that a hub for all the existing services would be created that will provide information and interconnection to the relevant to each request services...” **Neurologist, Day Care Centre setting**

“We do not put pressure nor exclude anyone...we try to find a suitable solution...In general I believe there are services – not many but they exist- however they do not reach to the final user... The majority of our services are provided online”. **Neuropsychologist, Day Care Centre setting**

“I do not think that the public services/organizations are enough to serve the needs of the people...There is also long waiting ... Also the connection of the services to the community is not good. (If someone is not able to reach our services) due to health issues or because they live very far away, we visit them with the care at home programme” **Social Worker, Day Care Centre setting**



*“We have created an online neuropsychological assessment battery...We investigate the initial request by phone... there is always communication by phone”. **Psychologist, Day Care Centre setting***

*“We have to prioritize the ones that have the most needs” **Nurse, Home Care setting***

*“I cannot exclude any person from our services...we are an organization that offers any service...for example now with covid this was an issue...some people that didn't have internet were excluded (from group cognitive training sessions) this is why we started doing telephone calls...they would be given the exercises in some way and we would call them at the end of each week to do them together...However in the setting we are in we cannot do everything...because we work with older people who might not be able to come to the centre themselves we have the Home Care service...basically a mobile unit with a doctor, neuropsychologist, social worker, nurse...they go to the user instead of the user coming to us...” **Neuropsychologist, Scientific Supervisor, Day Care Centre***

Theme 6: Monitoring and evaluation - tools used for the evaluation of care practices

Relevant Quotes

*“For people living with dementia I use psychometric tools, neuropsychological assessment. . . I use my clinical judgment. . . based on what I notice. . .”. **Psychiatrist, Home Care setting***

*“I record what I do in each and every visit I make in the database. . . For example, when I was doing the flu vaccines. . . I was getting information that I had recorded in the database about the dates. . . I personally take into account the feedback (verbal) I receive from the caregivers. . . how happy they are with my work. . . Occasionally, on the organization's newsletter several caregivers express their opinion. . . there is also an online group created by the organisation – I think on Facebook- where many caregivers express themselves. . .” **Nurse, Home Care setting***



“After a certain time of participation in the team- after a year or six months depending on the person- the neuropsychological assessment and neurological examination are repeated”. **Psychologist, Day Care Centre setting**

“ We always have regular communication with the beneficiaries and their caregivers, we hear back from the people participating in the teams as well as those who only visit the memory clinics...” **Neurologist, Day Care Centre setting**

“ We do not use a specific tool... so that the users can evaluate our services. At some point we did this by telephone, we phoned and ask them if they are satisfied with our services and if there is something we could change... it was useful we got feedback. It would be meaningful to give users an anonymous questionnaire about their satisfaction and for suggestions for improvement”. **Neuropsychologist, Day Care Setting**

“We keep a database with photographs of (wounds) to see their progress...We have a newsletter...often service users write in it and we ask them to write the good and the bad (about the association)...there is no perfect care...we set weekly goals” **Nurse, Home Care setting**

“The organization has an external supervisor that we have evaluation meetings with aa few times a year...We monitor the progress of our users by doing re-assessments each year...There are complaint letters that can be sent to the organization in case there is a problem...but because here the work becomes more personal after a while there is no official evaluation from the users...in the case of any small problems we hear about it from them personally” **Neuropsychologist, Scientific Supervisor, Day Care Setting**

“We do regular re-evaluation of the service users, we also have regular phone calls with the service users so we can be up to date with any changes due to their social, financial situations or due to the progression of the disease...Often service users have the possibility to express their satisfaction of



*our services either by phone or by sending a letter to the organisation...In the caregiver support groups I lead after the completion of the sessions I gave them an evaluation document that asked about their satisfaction with the programme as well as any complaints or comments or ideas they wanted to give” **Social Worker, Day Care Centre***

Theme 7: Barriers and solutions in person-centred care practice

Relevant Quotes

*“ I do not feel that there are barriers in providing personalized care in my practice. . . When there is a serious problem, I will discuss it with the organization and we will find a solution. For example, there was an incidence of abuse. . . in this situation we worked with the social worker. . . There is an organized sense and team spirit in the way we deal with the problems as well.” **Nurse, Home Care setting***

*“ The finances, the space, the number of healthcare professionals are limiting us... in providing personalized care... Taking this into consideration I think we provide something that is close to personalized care; something that is very much based in the ability and willingness of the healthcare professional to contribute to the care..” . **Psychologist, Day Care Centre setting***

*“ Due to the fact that we work in a mobile unit, the difficulties we face can be due to the fact that we cannot find appropriate workspace or because the responsible authorities might not provide us with the necessary equipment so as to provide our services in a faster and more efficient way” **Social Worker, Day Care Centre setting***

*“The physical therapists implement personalised care. You can not make a rehabilitation programme that is the same for every person... You should have the right approach towards the person, show them the exercises as something that is good for themselves and not impose them..” **Physical Therapist, Day Care Centre setting***



*“In an effort to cover the expenses we add more people and the programme might lose the personalised character... However, the team coordinators get to know the persons and implement specialised interventions in the symptoms management...” **Neuropsychologist, Day Care Centre setting***

*“There are many needs and few members of staff...we have a big workload and we are forced to place some people in a waiting list...we see each person once a week...in order for (the care) to be individualised we would need to see them more” **Nurse Home care setting***

*“The main barrier is the space of our centre...the fact that it is small and on the second floor...We have tried to create multi-use spaces so we can take advantage of the space as much as possible...the organisation setting does not interfere with our work too much...although the truth is that for example having only 1 hour to do a neuropsychological assessment is very little...however I have happened to take more time and there hasn't been a problem...the organisation management does not interfere with how we do our jobs” **Neuropsychologist, Scientific Supervisor Day care centre***

*“One thing that makes providing individualised care more difficult is the lack of an appropriate and well organised space along with an increasing number of requests of new users...moreover the health care professionals are not enough to cover the necessary number of individual interventions” **Social Worker, Day Care Centre***

Additional theme: Perceived meaning of person centred care

Relevant quotes

*« I am familiar with the person-centred or client centred approach, that of Rogers but not in detail. I perceive this term as an individualized therapy, specialized in each person based on their experiences, their story, their needs” **Psychiatrist, Home Care setting***



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“I do not know the term. . . I perceive it as (care)that focuses separately in each person. . . the patient has these specific needs; the caregiver has different needs. . .and I focus on each person separately and try to meet their needs”. **Nurse, Home Care setting**

“It is the personalized care; we adjust our approach on the special characteristics of the person...They might have common characteristics due to their condition but each one has different characteristics so this is how we approach them (based on their characteristics)”. **Neurologist, Day Care Setting**

“It is the personalized intervention for a specific person not for a big group...A specific person will have a specific care”. **Nurse, Day Care Setting**

“(We see them) as (different)personalities, each person requires a different approach even for the same symptom”. **Neuropsychologist, Day Care Setting**

“Person-centred care is when we take care of all the problems of a person, physical and psychological, we see them as a whole” **Nurse, Home Care setting**

“Person-centred care sets the person as the centre and all the services offered surround this person and their own individual needs...there is no specific guide that fits all...it depends on the setting and the characteristics of each person and their caregiver...otherwise anyone would be able to do it” **Neuropsychologist, Day Care Setting**

“ ... It is this kind of care that is tailored to the personal needs, the lifestyle, the abilities, the interests and the personality of the person. A personalized care programme that provides comfort, satisfaction, quality of life; structured with complete respect to the uniqueness of the person receiving the care”. **Social Worker, Day Care Setting.**



Fieldwork results Italy

IntegraCare: Person-centred care training program for multidisciplinary professionals

Phase 1

Fieldwork Results Template

COOSS - Italy

May 2021



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Preliminary observations:

These interviews and the focus group have been arranged with professionals working in two residential structures for elderly people with different disabilities, both physical and mental.

Theme 1: Care practices followed by the organization

Relevant Quotes:

“In this COVID emergency the residential structure is all their world and point of reference, so it's also more important to try to satisfy their needs and gratify their requests [...] also for what concerns a favorite meal.” (*Chef, in a residential structure*)

“You are here and you must be here, with them. They are people with specific needs and feelings and you have to consider this, not only the disease”

“It's very hard when you are in a residential structure with an agenda, protocols and specific timing and, above all, not a relation one-to-one. It's hard to centre 360° the person, but we try cooperating all together.”

“Empathy is the core of our work (*health care professionals*). I think that the relation and the human aspect should support people more than practical aspects. That means that concrete tasks are important, but to solve them we cannot forget the human relation”



“The host interest is always the centre of attention. We are their family and, if I had a 5 minute break but they need something, also a candy or to speak with someone, I prefer to spend some time with them”

“The problem is also the laps of the time and the restriction of timetable. Sometime tasks are overlapping and this make difficult to taking into account all specific needs”

Theme 2: Cooperation and coordination of multidisciplinary teams

Relevant Quotes:

Fundamental the multidisciplinary work (in Italy we use the French term “équipe” instead of “multidisciplinary group”): every person belonging to the équipe has a specific and irreplaceable role. Just to give and example: the health care professional cleans the host and notices an injury; he/she informs the coordinator and, finally, the doctor treats the injury. There is not hierarchy between different professionals, and decision are token all together”

“All professional working in the residential structure are part of the équipe”

“Before COVID we were used to have meeting every week. At these weekly meeting coordinator, health care professionals and nurses were used to take part. We were speaking about specific different necessity then usual or problem incurred or also about some goal or success. Now, whit COVID we don't have more.”

“After COVID, instead of weekly meeting, we have WhatsApp groups, or, if the question involves only few people, we are using emails or phone calls. But it's not the same. I prefers face-to-face meetings”

“The coordinator represents the point of reference of the team. Information are managed by him/her and he/she is the mediator of all decisions. He/she's the person who updates the team and who has the most complete vision about each case”

“Now, that due to the isolation measures of COVID, we cannot have periodical and multidisciplinary follow-up meetings, each day, the coordinator updates every professional about important new aspects; this means that both nurses, doctors, health care professionals, chef, physiotherapists, entertainers of elderly hosts have the possibility to know what they need to work in the best way”

Theme 3: Communication: use of person-centred language, attention to non-verbal communication

Relevant Quotes:

“The choice of the communication modality depends on type of assistance, ward in the hospital and related diagnosis/disease.”

“Social and psychological characteristics of each care receivers play a decisive role in a good communication”

“We have to underline the importance of the empathy, it means the ability to relate to the other by perceiving the loves of the other without making them one's own.”

“In residential structures the communication between caregivers and care receivers is fundamental because people are living there; the residential centre or the hospital, become homes, and – especially in this last year and half of COVID-19 isolation, caregivers become the main vehicle of information and connection with families”

“It is very important to know how people feel and respect their space and timing. It is about understanding the uniqueness of everyone.”

“One of the most important verbs we use is “to agree on”. From the beginning we research which are the specific interests of the person. Sometimes they collide with the professional’s point of view, so it is important to reach an agreement.”

“A big challenge/obstacle to enhance the communication aspects is the lack of time.”

“The worst aspect is the isolation of COVID situation that avoid any kind of external contact (and communication) and “steals” relationship time to manage security practices”

Theme 4: Involvement of the person the family and the informal caregivers

Relevant Quotes:

“Families are really important in the decision-making process, in order to know all details and needs of our hosts”

“Families are involved especially in the beginning, where people enter in the residential structures, but also when something change or an health problem arises. Before acting, we always meet families to agree together a solution”

“Before COVID all team were use to have personal contact with families, but now only the coordinator has”

“We collect families' feedback in different way, as for example during the weekly meeting they may have with their parents (before COVID they are used to come here quite all days, but now they cannot), but also with WhatsApp messages or phone call. To constantly communicate together helps both us, in the management of our work, and families, in the consolidation of a relation of trust”



“Families represent the will of the care receiver, that, generally is an elderly person with mental impairment, as dementia or Alzheimer, and is not able to take decision alone”

Theme 5: Inclusivity and accessibility of care services for dependent people

Relevant Quotes:

Not specific quote.

Theme 6: Monitoring and evaluation - tools used for the evaluation of care practices

Relevant Quotes:

“We use satisfaction questionnaires in order to gather information”

“We use specific PC program to manage all data connected to each single care receiver. This system allows us to share and not to loose any information”

“Before COVID we deliver an annual report about the services of residential structure. Last two years we have not the condition to collect all needed data to handle with this tool”

“I constantly gather direct and indirect feedback from care receivers, familiars, but also from other colleagues and this helps me to improve my work. I miss équipe weekly meetings”

Theme 7: Barriers and solutions in person-centred care practice

Relevant Quotes: Not specific quotes.



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Fieldwork results Spain

IntegraCare: Person-centred care training program for multidisciplinary professionals

Phase 1

Fieldwork Results Template

PREDIF-IB

26 February 2021



Erasmus+

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Theme 1: Care practices followed by the organization:

Relevant Quotes:

“It is important to be humble and if we cannot meet the necessities of someone it is better to look for another service which can.”

“We are experts at making suggestions. It is well known that this strategy is more powerful than imposing a supposed solution. So it is never imposed to act on a way or the other. We suggest and then is the person who decides.”

“We take into account the priorities of people we attend to. In our service, we create a plan. Before the creation of this plan, a professional arranges a meeting with the person and assesses what necessities he or she has. After that the plan is written. This plan includes instructions created by professional but always taking into account what the user has demanded.”

“The most important principle for me is self-determination. For us, it is crucial to help our users to create their independent life style project. Taking this into account, we’re going to provide them with the necessary tools to reach that goal.”

“Empowerment is also a meaningful principle. That allows people to go step by step to conquer the independent life we’re talking about, which implies for example getting a job.”

“People with disabilities are the ones who set the pace, we just accompany them in their process.”

“It is important to bear in mind that one thing is the person and other is his or her disease. We don’t treat diseases; we treat with people. It is essential to focus on the potentialities of people, not the consequences of their conditions.”



“Reaching an agreement with the person is essential, making him or her know that their voice matters.”

“Professionals mustn’t be prejudiced or have a judgemental attitude. Respecting the timing of everyone is an essential aspect.”

“Empathy is the most important concept for us. We listen and observe our users actively. Sometimes there are contradictions between verbal and non-verbal communication.”

Theme 2: Cooperation and coordination of multidisciplinary teams

Relevant Quotes:

“We’ve got meetings every week which involve the whole multidisciplinary team. In these meetings we just discuss about cases. They are very long, because we discuss extensively each case. We also have disciplinary meetings, which for instance involve all the psychologists. “

“We use an app called teams, WhatsApp, phone calls, emails and weekly reports”

“We also tend to gather information from external professionals.”

“When someone presents a different necessity than usual, I always consult the social worker. We coordinate ourselves, so we can meet that necessity or find external resources which can.”

“We make follow-up meetings frequently and periodically, so everybody is updated and knows what must be known about each case.”



“Multidisciplinary approaches are good, but it is also an interdisciplinary approach which is needed.”

“A common methodology which is clear for all professionals is imperative.”

“Our team is composed by psychologists, neuropsychologists, speech therapists, social workers, nurse assistants, occupational therapists and physical therapists. Every and each professional is important and gives information to the rest. This team is managed by a coordinator.”

“It is essential to have a fluid communication with external professionals, so when they know something new, they will say it to you immediately.”

“Informal meetings arranged by the organizations to allow professionals to know each other better.”

Theme 3: Communication: use of person-centred language, attention to non-verbal communication

Relevant Quotes:

“One of the most important verbs we use is “to agree on”. From the beginning we research which are the specific interests of the person. Sometimes they collide with the professional’s point of view, so it is important to reach an agreement.”

“Positive language is an important aspect of communication. For instance, an objective must be positively formulated. Another moment when we try to apply positive language is in interdisciplinary meetings. We try to avoid concepts such as limitation or problem. Instead, we use words such potentialities or abilities.”



“It is very important to pay attention to non-verbal aspects of communication. When I try to create a good atmosphere, which allows a good relationship to flourish, I always look at the eyes and when possible a make physical contact.”

“It is very important to know how people feel and respect their space and timing. It is about understanding the uniqueness of everyone.”

“Seeing the other person as an equal is an essential part to build an excellent relationship. It helps if you share some personal details about your daily life. It doesn’t necessarily need to be very deep. For example, what you did yesterday or some plan you have for the weekend.”

“Accessibility is mandatory when it comes to speak with our users.”

“Assertiveness is our most important communication asset.”

“Language should never be infantilized.”

“Humble language. Making sure people understand that we will never be able to solve all their problems.”

“We have to classify people. There are people who need a direct kind of communication and there are people who need a delicate one.”

“One good example of difficult communication is when I have to advice a family member to incapacitate his or her relative. In this case, I always explain the concept making sure they know it is beneficial and avoiding a feeling of guilt. Incapacitating someone sounds really aggressive, so I tell them that they are going to protect him or her.”



Theme 4: Involvement of the person the family and the informal caregivers

Relevant Quotes:

“The person participates in the decision-making process from the beginning. We have a great variety of settings where they can be attended. It enables them to choose where they want to receive the service.”

“Another way to involve them is to use satisfaction questionnaires or ask for suggestions”

“We try to make the person accountable. It is not just receiving a service; it is also what they do at home.”

“Each case is different. It is important to make them participate. We just want family members to participate when there are risks associated to the person we provide the service. Family members can also participate when it is specifically asked, making always clear who is the protagonist.”

“It is beneficial for family members to begin a process with us. It allows them to free up a lot of time. It is also very beneficial for them to learn how to set limits.”

“It is very important the bonding you establish. It will make the work easier.”

“A lot of times there are family members who are a little bit invasive, it is important they are listened to, but always setting some limits. The person with a disability has to be the protagonist. So what I do is try to connect both the objectives of the family member and those of the person with a disability.”

“It is important they understand the risks of their own decisions. For instance, if I recommend them the use of a walker, they can refuse. The necessity is still there, so they have to understand that if they fall, it is their responsibility. They have accepted the risk.”



Theme 5: Inclusivity and accessibility of care services for dependent people

Relevant Quotes:

“We are familiar with the concepts of advocacy and empowerment. We apply those concepts in a daily basis. For instance, when someone comes complaining and asking to report to the authorities, we empower them to do it by themselves. If the answer they receive is not adequate, as an organization we interfere representing the interests of the collective.”

“We’ve got a department which is focused on community participation. From this area they try to include people with disabilities into the rest of society, not just groups of people with other disabilities”

“The main attitude towards people with disabilities is to overprotect them. This attitude goes against their own autonomy, which is the most important goal for us.”

“In my service we provide people with disabilities with a personal assistant. The main job of personal assistants is to help people with disabilities in their daily activities which not involve caring. For example, in their job or in free time.”

“There still so much work to do in order to make all services more accessible to people with disabilities. In the health services, there’s a recent incorporation who is really useful. The “nurse case manager” is the one who centralizes all the information. It is very advantageous for us, she or he allows us to have access to relevant information without having to ask every specialist or doctor.”

“There’s a rigidity in some services. For instance, it is possible that an organization doesn’t want to intervene because of some mental health issues, they just attend physical disabilities.”



“Sometimes people see at social services as something which is only for poor people. This perspective must shift. It must be seen as a tool for everyone.”

“The social worker should be more accessible; they are indispensable to guide people through a lot of circumstances during their life.”

Theme 6: Monitoring and evaluation - tools used for the evaluation of care practices

Relevant Quotes:

“We use a system called MN PROGRAM, which allows us to have access a great variety of data. We also use a lot of excel files. It also allows each professional to register everything that happens with someone, so there’s no information lost.”

“We use a quality management system. We also create an annual report.”

“When a new case comes, I gather information making an initial assessment. This assessment helps to formulate the firsts objectives to work. As the person is being attended, I get more information which can make me reformulate those objectives or to formulate new ones. For instance, as we work self-esteem it can be possible to notice a lack of social skills.”

“Questionnaires and satisfaction questionnaires are the main tools we use to asses our work.”

“We gather the information we need by going in situ to where the people that need us are. We question directly the person who is receiving the service. We also take into account what other professionals, both from our organization or external, observe.”



Theme 7: Barriers and solutions in person-centred care practice

Relevant Quotes:

“The cultural attitudes towards people with disabilities are pretty negative. People tend to see them as an overload to society and as a highly expensive cost. The cause of this negative perspective towards disability is political. It is demonstrated that people with disabilities who have personal assistants are much more productive than those who are in nursing homes. Unfortunately, this is not the reality.”

“Sometimes it is difficult to coordinate because of a lack of time. Professionals are usually very busy, so it’s easy no to have enough time to make a call or send an email.”

“It happens frequently that the person who receives the services demands more than what is possible. In this kind of situations, we explain them assertively why their demands cannot be met. For instance, maybe they demand more physical therapy time than possible.”

“Indecision from participants is an important barrier.”

“Sometimes it is pressure from the rest of professionals. Maybe they believe psychology is necessary, but the person doesn’t want to work on psychological issues.”

“One big obstacle is the way people with disabilities are handled. It is usually believed that basic needs are the only one which have to be met. They are, of course, important but there also a lot of other aspects which are essential for everyone to have a meaningful life.”

“Our organization is financed by the administration. They set our limits, sometimes they are not reasonable. For example, it’s typical for us that someone demands and needs more time than what we can offer.”



Fieldwork results Poland

IntegraCare: Person-centred care training program for multidisciplinary professionals

Phase 1

Fieldwork Results in Poland

MIS Foundation

May 2021



Erasmus+

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METHODOLOGICAL APPROACH

The study and fieldwork on was conducted to methodology approach and Interview guidelines that two project partners has developed: AAARDS and TTHU.

During these phase of the work:

- We conducted the online interviews with the 6 experts – the care professionals.
- We organized one focus group with 6 experts - the care professionals

The participants of the interviews and the focus group has represented various institutions operating in the field of social care. The experts work in facilities that provide care services for dependent people (for various reasons: age, old aged disease, mental disorders, intellectual disabilities, chronically mentally illnesses, etc.), in the form of daily or 24/7 hours support: the Daily Support Centre, the Environmental Self-Help Home or the Social Welfare Home.

The participants of interviews and focus group has represented different care professions, as the following:

Interviews	Focus group
1. Psychologist	1. Psychologist
2. Social Workers	2. Social Workers
3. Social Workers	3. Social Workers
4. Therapist	4. Therapist
5. Therapist	5. Coach
6. Therapist	6. Physiotherapist



MAJOR FINDINGS OF THE FIELDWORK

Topic 1: Care practices followed by the organization.

All the professionals we talked to said that in their work with dependent people they use a strategy based on the individualization of support for the charge (the approach based on the principles of Person-Centred Care).

Diagnosing the individual needs and capabilities of the person they care for is crucial in determining the standard of support and the Individual Support Plan. The scope of support depends on the type of institution, the tasks it performs and the type of beneficiaries.

For example, the scope of care services provided in a Social Welfare Home (24-hour facility) is very wide, from nursing, hygienic, medical (prescribed by a doctor) and medication to therapeutic, psychological, social support and other. In the case of daily support facilities, the scope of services they provide includes therapeutic, rehabilitation, psychological and social activation support (with vocational elements), which prepares the participant to live in society and function in the environment.

In each case, at the very beginning, the participant - the dependent person - is diagnosed. Its purpose is to get to know the psychophysical state of a person, health situation, and identify the person's needs. Before starting the support, the social worker conducts *a community interview in the neighbourhood* where the participant lives. This interview allows to establish the family and health situation. The basis for determining the health situation of a person is also medical documentation, which often does not show the full picture of the health condition of the participant.



Based on: *external documentation* (e.g. medical documentation), *community interview in the neighbourhood* and conversation with the participant, an *Individual Action Plan* is developed according to which support for the person is implemented.

Everyone emphasized that the most important thing is to build a good relationship with the dependent person from the very beginning. The most important thing is: respect for the dignity of the person, show care and interest, safety.

Relevant Quotes:

“The diagnosis is of key importance according to which standard we will be able to respond to their needs.”

“The resident on the first day is stressed by the situation because he changes his place of residence. We don't want “to bombard him with care" because he can get lost. This is the stage of introducing and adapting the inhabitant. It is also the time to get to know the resident, also whether his declaration that he wants to live here (in the Social Welfare Home) is authentic, or whether he is sacrificing himself (e.g. for the family). At this stage, it is important to build the relationship: "Resident - staff". To reach the resident means: listen, do not offend, do not force a relationship, do not force openness, it will happen over time.”

“The stage of getting to know the resident with the facility (“new home”) is always guided, but it is not such a “rigid” path (following the procedure). There is a nursing diagnosis, i.e. an assessment that serves to develop an individual nursing care plan. But it is important to know person daily customs, also person beliefs (it is also important to know, for example, which religious celebrations are important to him/her), activities, and preferences.”



“It is more important that the person sees that someone is interested in them, not ticking off the points of the procedure.”

“Respect for human dignity - in each person we see a person who requires respect not because of what he has achieved so far, but in general.”

“We show concern and interest”.

“Feel safe so that he does not feel threatened”.

“Maximizing our commitment to his life. Our concern does not stem from regulations but is genuinely at the centre of our concern. We do not want to replace the family, but we want to be friends with him”.

“We use the resident's potential to be active. To make him feel safe here. But also does not close the world for him.”

“The most important rule – subjectivity.”

“We support people who require long-term care and the most important rule is to provide them support similar like at home (keep home conditions). To create conditions of intimacy, conditions to meet basic needs, ensure contact with the family. To be a real home "tailored" to the needs of the inhabitants.”

“The action plan depends on the elderly person. We will not live our lives for them.”



“Diagnosis, identification of needs, individual support plan - from the perspective of various specialists, identifying the needs and capabilities of a person. The person decides to what extent he wants to participate in certain processes, to what extent he can participate in certain processes. With a person in the family home – it can be done with the family.”

“It's all relationship work.”

Topic 2: Multidisciplinary teams: cooperation and coordination between different professional fields.

In each facility where our interlocutors work with dependent people, there is a multidisciplinary team that takes care of the participants. The composition of the fixed multidisciplinary team depends on the type of facility and the psychophysical and health situation of its participants. Each facility also cooperates (formally or informally) with other specialists (who are not included in the permanent composition, and their knowledge and experience is useful for providing support)

The permanent team most often includes: a social worker, therapists from various disciplines, a psychologist, a physiotherapist, a nurse (generally, only in case 24-hour social welfare homes).

Relevant Quotes:

“We organize meetings of a therapeutic and care team composed of specialists from various disciplines. First, they rely on external documents (e.g. medical records) and their own tools to determine the psychophysical state of a person, health situation and the possibilities that our facility has at its disposal”

“At the meeting, the therapeutic and care team selects the first contact employee for the new participant - for the adaptation period. The model solution would be if this person - the first contact employee - was indicated by the participant himself (the resident). But in the beginning, the resident has no knowledge of the facility staff.”



“When a new person is admitted to the home, there is a social worker and a representative of the nursing and care team - most often it is a nurse. The psychologist, the therapist is on the next day in order not to overstress the new resident.”

“Depending on his physical and mental condition, an appropriate team of employees is selected for the resident.”

“The participant is not immediately assigned to a specific therapeutic (thematic) activities. First, she/he participates in the various activities for 1 month. We try to gather basic information based on the interview with the participant. Here, contact with the family is also very important. Than after this first month, the participant is assigned to specific therapeutic activities according to his psychophysical abilities and interests. This is determined by the activating and supporting team (therapists and psychologists)”

“From the very beginning, the residents of our Social Welfare Home are looked after by a team consisting of specialists with various disciplines. It is done by a team of specialists, which includes: a social worker, a psychologist, a nurse, a doctor, a physiotherapist, and other specialists, depending on the psychophysical situation of the resident (e.g. the SWH cooperates with the psychiatry clinic of the Clinical University).”

Topic 3. Communication: use of person-centred language, attention to non-verbal communication

The participants of the interviews and the focus group emphasized the importance of communicating with the participants / residents. First of all, attention was paid to the “language of communication” - positive, respectful, without negative emotions. Depending on the facility, the staff addresses the participants/residents using the form "Mrs" or "Mr" with the name or only by name (In the Polish linguistic and cultural tradition, when addressing an adult, the first name is used with the pronoun “Mrs”/”Mr”). In communication with the participants, the team behaves so that the participant does not feel inferior (due to illness, disability or other conditions). It is also



important to use the appropriate language of communication when performing treatments (e.g. during treatments not to talk about matters other than those related to the person, or not to use negative language in communication). One of the interviewees said that communication is one of our basic programs. There are communication workshops for staff on how to communicate with residents/participants.

Relevant Quotes:

“We don't use the word “a customer”, but “a resident”, “a person”. The concept of "a mentees" also does not reflect this relationship between the person who needs help and the caregiver.”

“Communication - is one of our basic programs.”

“We use the language with respect”

“We participate in the process of organizing help. We, the staff, are not experts on the life of Mrs. Maria, because she has lived through hers. She will allow us to see herself, her feelings, to the extent that she wants to.”

“We talk to each other by either giving the name (e.g. Maria) or "Mrs. Maria".

“Sometimes, the staff warms up contacts and the language of communication, using very diminutive forms (e.g. “Mr. Januszek, we will iron shorts” instead of trousers - a message to a 90-year-old person. It's not good”

“In the case of people with increasingly progressive disease, we communicate from the beginning every time, because the person cannot remember what was said 5 minutes ago.”



“The quality of the message and the vocabulary are important - repeated messages, even asking for confirmation of understanding.”

“Here we have people with a lot of experience, but also with a different physical and mental condition. The way you communicate with them varies.”

“Physiological intimate matters are not taboo in communication. A person must not have a feeling of humiliation, violating his privacy. For example, we say "Mrs Maria, now we will change pampers" - so we will do it together.”

“Sometimes we see that some people are not getting the right message. Sometimes it happens that two nurses are telling each other something while moving the bed with the person. We say "tell the person about it, not to the other nurse". For example, “Mrs. Zosia, I am so glad that my daughter got a high grade at school”.

“In the process of communicating with a person, we do not try to take on the role of a parent. We indicate and suggest what a parent can do, but we do not fall within the parent's or legal guardian's competences.”

“If we have the opportunity to get to know a person, what are their priorities - this is important to us. When the moment comes that an (elderly) person loses consciousness, we are able to respect it. Before age takes away my ability to communicate. We can take care of the welfare that is possible.”

Topic 4. Involvement of family and informal caregivers.

The family and informal caregivers are constantly included in the care and support of dependent people. This is done from the very beginning stage. At the stage of admission to the facility, an interview is conducted with the family in order to find out about the interests of the person and



their possibilities, the degree of independence the person is in the home environment, etc. This interview with the family allows you to get to know the person, their current habits, and choose the appropriate forms of support.

During the residents/participants staying in the facility, the family is informed about the progress in developing competences, being independent, psychophysical and health condition. It is important that contact with the family is constant and, as far as possible, regular. Although it is not always possible (there are cases, e.g. the family of elderly people staying in Social Welfare Home loses contact with the person, does not maintain contact, is not interested).

Relevant Quotes:

“In our opinion, working with parents is very important. Regular contact with parents allows us to verify the activities. We inform about our plans, what we would like to implement, we invite parents to join the activities. The flow of information works both ways. Before the pandemic, meetings with parents were organized every two months. Now they are mainly regular telephone contacts.”

“Our centre is open to parents and the family members”.

“We are in constant telephone contact with the family. Each family member can come to the centre to see how their child or mentee is doing during the classes. We invite parents to participate in various events, such as excursions.”

“We have a special cooperation program for the families and caregivers of participants using the support. The program consists in organizing a weekly support group for family members with two specialists (therapist, psychologist) where various problems and situations that occur in the home or environment are discussed. There are also duty hours (stationary and by phone) for families.”

Topic 5. Inclusivity and accessibility

The facilities that provides services for the dependent people operate on the basis of specific legal acts and they are financed from public funds. The scope of services that facilities provide to their residents/participants results from these legal provisions. These facilities operate on the basis of the necessary internal documentation, approved by the body running the facilities. These include: the statute of the facility, internal regulations, activity program and the annual work plan. The head of the facility is responsible for their preparation.

There are situations where the needs of participants / residents exceed the standard of service specified in legal regulations. Then, if possible, the facilities and their staff try to meet these expectations and needs, also involving the family. This is done in different ways. One of the examples is the implementation of tasks that go beyond the standard of services by people, institutions, organizations, engaging volunteers cooperating with the facility. Another example is the establishment by the parents of dependent persons of an association for persons with disabilities, the aim of which is to provide additional support for dependent persons, and to obtain additional financed funds - participants of this facility, in close cooperation with the staff of the facility.

Relevant Quotes:

“Advocacy: We very often advocate our people in various matters. For example, we help to get an appointment with a specialist doctor, or we prepare a justification that the person is entitled to purchase prescription drugs for 75% of the price. We are advocates of people towards the doctor.”

“We are advocates for, for example, social institutions - in terms of social financial help for dependent people”.

“It happens that we are advocates for the family - for example, if the person is in conflict with the family. This may be inheritance, debts, etc.”



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“We are constantly engaging various people and institutions in various activities. For example, before the pandemic, a group of 5-year-olds children from one kindergarten in Kraków-Płaszów (with the consent of their parents) came every month on Monday and had joint activities with the residents. Schools organize events and parties for residents. We have volunteers, artists come to perform.”

“There are people who have different needs during their stay at the facility, e.g. one of them wants to go abroad once a year. We help her with all travel formalities. One person has lost a leg and is in a wheelchair. First, we organized rehabilitation (which is standard service), but we also organized a fundraiser for a prosthesis”.

“Rehabilitation – we cooperate with an additional external company that acquires external funds for such services”.

“Legal counselling - one person had a problem that required the help of a lawyer”.

“The most important role in making decisions is the diagnosis and definition of the care plan”.

“We cooperate with the University's Psychiatry Clinic - they provide support once a week”.

“Most often, a team of specialists makes a recommendation for further support. In part, the person also participates in it. We conduct a dialogue about what the person expects and what they would like to achieve. This process of a person's participation in the planning of activities is ongoing. But, there are people who don't want to be offered anything. They decide for themselves.”

“The parents established an association for people with disabilities and this association works with us in the implementation of joint activities.”

“If someone from outside is needed, it must be done with the consent of the resident.”



“Can we afford a standard for everyone with very different needs? It is difficult to establish an offer, e.g. for an intellectual person and an addict. The offer is for everyone, but everyone has the right to choose.”

Topic 6. Monitoring and evaluation

The facilities and professionals use very different tools to monitor and evaluate the services provided to dependent people. These include interviews, observation, verification of the action plan and achieved results, super-revision, reports / service cards, etc.

Relevant Quotes:

“We use various monitoring and evaluation tools. Daily Reports - Nurses: these are all day and night reports for your supervisor. Social workers - social work cards. Therapists' work cards. The cards of psychologists. Monthly reports of everyone. All this is collected and is the basis for the whole team to talk about an individual care plan and its modification. Manager approves. Verification of what has been achieved at the next meeting. The ad hoc control is carried out by the director”

“We talk everyday about our matters, problems, observations, situations that we want to discuss and discuss with the entire team.”

“We have meetings with a psychologist who supports us”

“An individual support plan for a person is prepared for 1 year. Each plan is not fixed. The team meets and analyses whether the plan is feasible, whether the person is able to implement it, whether the plan is not too intense and requires modification. If there is a need, the team sets other goals. In the case of people with multiple disabilities, the “rule of small steps” applies. Participant accept plan.”



“Therapists keep notebook of observation. They are discussed every month. Is there a change, is there anything to change in the support plan, etc.”

“Evaluation takes place every six months. We monitor our activities on an ongoing basis all the time”.

“We use various tools in the monitoring and evaluation of the supporting process. First of all, it includes: weekly meetings of the team and half a year meetings when the action plan is verified and modified.”

“We use supervision of work that is conducted by a supervisor, who is a psychiatrist and psychotherapist working in one of the hospitals in Krakow (in the hospital ward on personality disorders and neuroses). It helps us a lot I our work and further development”

Topic 7. Barriers and solutions

Financial barriers, i.e. limited funds for the operation of the facilities, were among the most important barriers indicated by the survey participants.

Relevant Quotes:

"Undefined role of a Social Welfare Home. We should have a large healthcare service - because of the people who are here, in the Social Welfare Home. And this range of services is poorly financed, as nursing services are the responsibility of the Ministry of Health and the area of healthcare system, and we are subordinate to the Ministry of Family, Labor and Social Policy and the area of social policy.

“Sometimes we would like to do something more for our participants, but we cannot because of the financial barrier (government subsidies that determine what tasks we can finance). The funds we get are counted per 1 participant, which is not sufficient for all activities and needs reported by participants.”

