





# Pathways to independent living for mental health in three capitals of southern Europe: Madrid, Lisboa and Roma







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The associations were created by family members, when the need to respond to the needs of social integration resulting from the closure of mental hospitals and before prolonged hospitalizations in hospital environments was not fully satisfied by public services.

They have different purposes and consistency, and their diversity is also the result of the territorial scenarios in which they operate, where the social rehabilitation of people with mental problems has been addressed with different regulations and provisions from the public authorities.

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#### Abstract- Results of the partnership Solaris-Amafe-Gira

- Recovery as an intervention model across the 3 countries, with proven results;
- Importance of their own participation (mutual aid groups, organization of activities for peers, self-representation and defense of their rights);
- Recognition of the role of families, calling for their involvement and participation and providing support;
- Need for investment, with a strategy in mental health policies, based on scientific evidence and in the organization and articulation of services and responses (covering existing needs);
- Recognition of the importance of community structures, such as the family associations we represent;
- Importance of research and follow-up studies;
- Importance of the effective participation of bodies that represent family associations and users for the implementation of mental health policies, effectively necessary for people.

# INTRODUCTION: PATHWAYS TO INDEPENDENT LIVING FOR MENTAL HEALTH IN THREE CAPITALS OF SOUTHERN EUROPE: MADRID, LISBOA AND ROME

This toolkit is aimed at families, their community organizations and stakeholders interested in the social inclusion of people facing mental health problems and in spreading information and knowledge about the role of families and their organizations. With the introduction of community-based care the responsibility for care falls mainly on the family and the person's social network. Families care for someone who can have attacks of acute psychosis; show little motivation for most activities; be self-centered most of the time; hardly contribute to the family; has cognitive difficulties that give rise to forgetfulness, misunderstanding, irritability, frustration and sometimes open hostility.

Families are initially completely unprepared for the challenges of this role and often need the professional assistance and resources to help with individual care and management, as well as links to self-help support.

The creation of family associations is a direct consequence of the need to address problems in inclusive terms, and their mandate is to promote the public interest and serve the public good rather than only advance the interests of one family or a narrow group of individuals.

Let's remember that the situation in Europe is worsening in terms of mental health. The data that the European Union released in June 2023 are disheartening. The situation has worsened in the last three years:

- Until 2019, 1 in 6 people suffered from mental health problems, now
- 46% of EU citizens have had an emotional or psychosocial problem in the last 12 months;
- 89% of EU citizens consider promoting mental health to be as important as promoting physical health
- 25% of EU citizens have experienced problems accessing mental health services for themselves or a family member

The responses that the European Union has envisaged concern funding for three major development directions:

- a) Prevention
- b) Access to quality services
- c) Reintegration into society after recovery

The three guidelines recognize as priorities actions aimed at young people (a target group which has seen exponential growth in the use of social and health services in recent years), the improvement of services (which must adapt and be flexible, adapting to new needs), to social and work inclusion after the recovery paths that health services carry out in the presence of crisis situations. The new EU documents recognize "the importance of family, community, economy, society, environment and security" in these paths of re-appropriation of active life.

The family has become one of the pieces to count on in the processes of social inclusion. Already in 2010, the World Health Organization published «User empowerment in mental health - a statement

by the WHO Regional Office for Europe », stating that "Historically, people with mental health problems have lacked a voice. Neither they nor their families have been involved in decision-making on mental health services, and they continue to be at risk of social exclusion and discrimination in all facets of life".

In this text, the family members are included as informal operators, also citing a study by Rethink (UK) where it emerged that:

- "- 95% of the operators are family members of the users;
- 29% provide assistance and help for more than 50 hours a week;
- 90% are also affected in various ways by assistance tasks in the areas of free time, professional career, finances and family relationships;
- 60% have a significant or at least moderate reduction in social life;
- 33% find that family relationships are seriously compromised;
- 41% have significant or moderate mental health problems"

Family members activities must be valued and supported (European Framework for Action on Mental Health and Wellbeing, 2016), recognizing their role in the support network for these fragile persons and the World Health Organization, in the "European Mental Health Action Plan" (2013-20) invites States to «create opportunities for service users and/or families to plan their own services by providing budgets, with a clear responsibility", that is, allocating clear financial help so that they can create services that respond to their needs.

Even if paradigm is changing and in the new documents service users and family members are mentioned as possible active subjects in the social reintegration process, still today there is no reference to Family Associations.

And now, at a territorial, national and international level the needs emerged to strengthen the information:

- On the activities that the Family Associations carry out to facilitate the social inclusion and personal development of people facing mental health problems, whether they are family members or patients of the social and health services;
- On activities involving the local area and which help to break down the stigma and prejudices that still exist towards people with mental health problems;

for the recognition of family members' organizations as an active part in the recovery paths of their loved ones.

This toolkit wants to respond to this need with a Compendium that collects the documents elaborated with the project "Families and Independent Living in Mental Illness" (Erasmus+ 2022-1-IT02 -KA210-ADU-000083445), by three family organizations: AMAFE, from Madrid, GIRA, from Lisbon and SOLARIS, from Rome, which is also the coordinator of the project.

This toolkit is aimed at families, their community organizations and stakeholders interested in the social inclusion of people facing mental health problems and in spreading information and knowledge about the role of families and their organizations.

The contribution of this Compendium is spreading the role of these organizations on the path of people looking for supported housing solutions, through information on their active participation in the recovery paths of their loved ones, on the activities to facilitate their social inclusion and personal development, involving the local area and break down the stigma and prejudices that still exist towards people with mental health problems.

In particular, it contributes to strengthening the role of family organizations by providing information on the services they offer:

- a) framing them in the different regulatory systems of the three territories.
- b) providing examples of the activities and some good practices carried out in three different cities: Rome, Madrid, and Lisbon,
- c) highlighting their role and activities in community care.

#### Each partner presents three reports:

Report 1: "Health and Social Services provided in the Communities", with the analysis of the tools and means provided by public and private services to facilitate the housing solutions of people with mental disorders, from the exit of the family of origin to the transition to sheltered accommodation or independent accommodation. It consists of collection of information on national and local legislation, even minor ones, and on the provisions adopted by local communities.

Report 2: "Activities of the Family Organizations in Madrid, Lisboa and Rome", with the summary of the activities of the three associations and some indications on national family organizations, also realized by the job shadowing experiences that each association makes in the cities of the partners. These activities contribute to the independent housing of their members, intervening a) on families, b) on institutions and c) on people with serious problems of mental health.

Report 3: "Good Practices of Family Organizations": from the activities carried out by these organizations, some good services can be taken as examples, even with due recognition of the difficulties that characterize them. Each partner described two good practices for the empowerment and autonomy of these persons: the actions undertaken, the results obtained, taking into consideration the three subjects involved: people, families, public services.

The information provided by these reports is of interest to many persons:

- the members of the family organizations will be able to use it in their personal growth and in the projects and activities that they promote, in the realizations of the events, in publications, seminars and in all the training activities that they will undertake to improve the performance of families in the difficult role of supporting their loved ones;
- people with severe mental health problems can have larger knowledge of the elements and difficulties involved in the path towards independent housing, but also of the elements that contribute to the success of the path undertaken by some of them.
- the stakeholders and policy makers will be able to support the family organizations and the people with mental health diseases with more

All this documents will contribute to breaking down stigma and prejudices against this people and the families that support them. Therefore the benefits of this documents concern the individual, the family and the public and private services.

Furthermore, the information offered by these Toolkit:

a) brings out the methods and strategies to clarify the strengths and weaknesses of the role of families and organizations, while collaborating in the recovery and independent life of their loved ones, with greater transparency and appropriateness;

- b) facilitates the identification of the elements to create new good practices, through the experiences made by organizations operating in different cities;
- c) offers content, knowledge and food for thought on the results obtained which are disseminated through meetings, conferences and websites, promoting the development of new methodologies and activities even among subjects who have not taken part in;
- d) strengthens the role of family organizations with a base of shared on-the-job knowledge and experience, creating a first transnational network of family associations active in the field of support for independent living;
- e) contributes to sensitize policy makers in supporting autonomous housing paths for people with serious problems of mental health, offering them new and innovative intervention tools that have also been tested in different cities;
- f) becomes way for disseminating knowledge on interventions and good practices in other territories and in other sectors, collaborating in the fight against the stigma and prejudices that accompany the daily life of people with severe mental disorders.

# CHAPTER I – SERVICES AND SUPPORTED HOUSING IN MADRID, LISBOA AND ROME

Introduction

The analysis of the scenarios where AMAFE, GIRA and SOLARIS are working represented an important step to contextualize the work of the associations in their territories. For this first Report the analysis, themes and a common index were agreed upon, which was adapted based on the results gradually obtained.

The results of the investigations carried out by the partners show the following situations:

**In Italy**, law 180 of 1978 led to the closure of mental asylums, in the Lazio region this closure took place twenty years later and recovery and rehabilitation were managed by the Health Departments and by their local structures, which also manage the Day Centers and brief work placements.

In Rome: there are four typologies of residential solutions: "Residential Facilities for Psychiatric Treatments", that replace hospitalization in hospitals, which has been abolished, and are offered to the person when suffers a crisis; "Residential Therapeutic-Rehabilitative Facilities" and "Residential Socio-Rehabilitative Facilities", with short periods of rehabilitation, are oriented towards therapeutic or social rehabilitation with care support all the days. "Flat Groups" are housing solutions with only a few hours of supervision per week.

In addition to these supported homes, Day Centers and "Planned Home Care" services are available for those people who want to live in independent apartments.

**In Spain**, in 1997 the different Specialized Centers of Social Services are in charge of the Public Service of Social Care, Psychosocial Rehabilitation and Community Support for Persons Affected by Serious and Chronic Mental Illnesses.

In the Community of Madrid: there are "Mini-residences", with social care support all day, every day; "Controlled Apartments" and "Controlled Pensions", with care support from 10 to 20 hours per week, while for people who use the houses of the "Reintegration Support Services" the support is minimal and varies according to decisions of the team.

The supported accommodations are organized and financed by the Councilor for Social and Family Policies of the Autonomous Community of Madrid and are part of the "Social attention network for people with serious and permanent mental illness" which is made up of a "Social assistance service", "Psychosocial rehabilitation centres", "Occupational rehabilitation centres", "Day social support centres" and "Community social support team", of the department of Family, Youth and Social Policy.

**In Portugal**, in 1998 the Joint Order "Feasibility of psychosocial rehabilitation programs in Portugal" allowed private associations to offer residences to people leaving psychiatric hospitals, with the support of teams dedicated to their social reintegration.

In Lisbon: there are different residences "Protected Life Units" and "Autonomous Living Units", created from the 1998 legislation, in which social and health support is moderate. Since 2010, a National Network of Integrated Continuing Care for mental health has been created, with new types of residences: "Maximum Support", "Moderate Support", "Autonomy Training" and "Autonomous", having different levels of social and health care. In addition, the "Day Centres", the "Community

Mental Health Teams" and the "Home Mental Health Support Team" are present in the Lisbon territory.

In addition, the "Employment Forums" (Day Employment Centres), the "Community mental health team" and the "Mental health care home support team continuously integrated" are present in the territory of Lisbon. In the three European capitals, the organization of social and work services aimed at the rehabilitation, inclusion and integration of people with mental problems is different: the resources and housing facilities put in place, the teams that support the people and the methodologies adopted to facilitate their inclusion are different.

In these territories there are several and different services, that under the direction of health services (Italy) or social services (Spain) are offered to people and families facing mental health problems.

This analysis, although not in-depth, offers us the scenario that allows us to better understand the services offered by the family associations in these territories, which are the topics of the second report developed by the three partners.

#### I.A – SERVICES PROVIDED IN THE COMMUNITY OF MADRID

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- 3.4. Law 16/2003, of 28 May, on cohesion and quality of the National Health System
- 3.5 Decree 122/1997, October 2, 1997 Basic Legal Regime of the Public Service of Social Care, Psychosocial Rehabilitation and Community Support for Persons Affected by Serious and Chronic Mental Illnesses, in the different Specialized Centers of Social Services.
- 3.6. Ley 1/1992, 12 March, Tarifas y Precios Públicos de la Comunidad de Madrid.
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#### 1. Introduction.

#### 1.1. Characterization of the territory of the Spanish health system

The healthcare system in Spain is decentralized and is governed by the General HealthLaw of 1986, which establishes the bases of the national health system. Under this law,health is a competence transferred to the autonomous communities, which means that each community is responsible for guaranteeing health care to its citizens. At the state level, the Ministry of Health is responsible for establishing general health policies and coordinating the actions of the different autonomous communities.

Although the autonomous communities have a certain degree of autonomy in the management of their healthcare systems, they must all be subject to the legislation in force at the national level. For example, the Law on the Management of Health Professions establishes the competencies and functions of health professionals throughout the country, and the Law on Cohesion and Quality of the National Health System establishes the principles and objectives of the health system, as well as the mechanisms for evaluating and controlling the quality of health care.

The Community of Madrid is made up of 179 municipalities and 21 districts. The main difference between the two is that the municipalities are territorial entities with autonomy to manage their own territory and resources, while the districts are administrative divisions within the city of Madrid and are part of the metropolitan area.

The districts are administrative units that depend, like the municipalities, on the decisions of the Community of Madrid, on the other hand, they have the Madrid City Council, which is formed by a mayor and 57 councilors, while the municipalities have their own city council, composed of a mayor and several councilors depending on the size of the municipality, where political decisions are made and public services such as garbage collection, street maintenance or water management are managed. In terms of political organization, the Community of Madrid has a president for the whole community and a Council of Government, which is its executive body.



The management of public health services depends on the Community of Madrid, although the municipalities and districts manage some aspects of the logistics of each device according to their territorial scope or areas. In short, the Consejería de Sanidad de la Comunidad de Madrid is the body in charge of coordinating and supervising healthcare throughout the autonomous community.

Each municipality in the Community of Madrid has its own health center, where primary care services are offered, such as medical consultations, nursing, pediatric care, geriatric care, and prevention and health promotion services. These health centers are managed by the Madrid Health Service (SERMAS), which is the body responsible for coordinating and financing health care throughout the autonomous community. In addition, some larger municipalities may have public hospitals, which offer hospital and specialized care services.

#### 1.2. Health system in force in Spain and in the Community of Madrid

In turn, the Health Management Act establishes the legal framework for the planning, organization and management of public health services in the Community of Madrid. For this reason, the Network of Public Mental Health Services covers both the districts and the municipalities of the Community of Madrid. This law stipulates that the Community of Madrid is responsible for guaranteeing health care to the entire population, and formalizes the criteria for the planning and organization of health services.

The procedure followed by the person with mental health problems in the Community of Madrid is as follows:

- <u>Primary mental health care:</u> If a person with mental health problems needs hospitalization, he/she is admitted to a psychiatric unit of a general hospital of the Community of Madrid. If it is not necessary, he/she may be referred to a CSM to follow a treatment plan.
- Referral to a Mental Health Center (MHC): Once the person is discharged from thegeneral hospital, he/she is referred to the MHC corresponding to his/her basic health area. At the CSM an initial evaluation is made and a treatment plan is established, from here they are referred to the rest of the resources of the Mental Health Network. As we have mentioned, hospitalization is not a prerequisite for access to the CSM.

<u>-Referral to a residential resource</u>: Depending on the severity of the symptoms, the person may be referred to a residential resource through the **Continuity of Care Plan**, which is coordinated by both the Regional Ministry of Health and the Regional Ministry of Families, Youth and Social Policies. These resources may be supervised apartments, residences or rehabilitation units. In these resources, accommodation, social care and support for rehabilitation and social integration are offered. Specifically, although there is coordination, it is important to emphasize that these services are part of the Department of Social Policies.

- Access to the services of the Mental Health Services Network: Once health care has been initiated, the person can be referred to services such as the Day Center, the Psychosocial Rehabilitation Center (CRPS) or the Labor Rehabilitation Center (CRL) of the basic health area in which he/she is registered. These centers offer outpatient care and focus on the psychosocial rehabilitation and labor reintegration of the person.

# 1.3. Incidence of mental health disorders in the national territory according to the BDCAP.

According to the report "Salud mental en datos: prevalencia de los problemas de salud y consumo de psicofármacos y fármacos relacionados a partir de los registros clínicos de atención primaria" by the BDCAP (Base de Datos Clínicos de Atención Primaria), data on care for people with mental health problems in the outpatient and inpatient setting at national and autonomic level are presented, corresponding to the year 2019. In the outpatient setting, a total of 2,842,896 mental health consultations were recordedin Spain, representing a rate of 60.74 per 1,000 inhabitants. In the inpatient setting, a total of 255,462 hospital discharges for mental disorders were recorded in Spain, representing a rate of 5.45 per 1,000 inhabitants.

In relation to the Community of Madrid, it is observed that this region presents a rate of outpatient consultations for mental health problems of 67.15 per 1,000 inhabitants, slightly higher than the national average rate. In 2019, a total of 201,657 attentions weremade to people with mental health problems. Of these attentions, 60.5% were performed in the outpatient setting, 31.6% in hospitalization and the remaining 7.9% in other care devices.

In terms of diagnoses, neurotic and depressive disorders are the most frequent, accounting for 38.7% of all consultations. They are followed by personality and behavioral disorders in adults (15.3%) and organic mental disorders (12.9%) in the outpatient setting, and as for the inpatient setting, neurotic and depressive disorders are also the most frequent in this setting (32.4%), followed by psychotic disorders (16.3%) and organic mental disorders (14.5%).

On the other hand, the Mental Health Plan 2018-2020 indicates that 20% of the population of the Community of Madrid has some type of mental disorder, which is equivalent to about 1.5 million people. In addition, it is estimated that 5% of the Madrid population uses mental health services each year.

#### 2. Residential resources for people with mental health problems

We call "residential resource" a form of care and accommodation for those who require continuous support and care due to situations of vulnerability, dependence or disability. These are establishments or centers that provide a living environment adapted to the needs of people who cannot live autonomously due to their personal situation of vulnerability, dependence or disability. These resources are designed to offer a safe environment, with specialized care and professional support, with the objective of promoting the quality of life, personal autonomy and well-being of the residents.

Residential resources can vary according to their nature and characteristics, and are adapted to different user profiles. Some common examples of residential resources are:

<u>Nursing homes for the elderly:</u> These are centers that provide housing and comprehensive care for people over 65 years of age who require assistance in their dailylives, health care and companionship.

<u>Residences for people with disabilities or major dependencies:</u> These are centers designed to meet the needs of people with physical, mental or sensory disabilities, providing them with housing, personalized care, therapies and activities adapted to promote their quality of life, increase their autonomy and prevent deterioration.

<u>Residences for people with mental illness:</u> These are centers specialized in providing housing and care for people who are under the PCC (Continuity of Care Plan) of the CSM from which they are referred.

## 2.1. Residential resources for people with severe mental health problems belonging to the Community of Madrid

In order to address residential services aimed at improving the quality of life of people with mental health problems, as well as preventing their deterioration and promoting recovery, we have divided residential resources from resources for independent living support into two different lists, but both have in common that they are public in nature and belong to the Mental Health Social Care Network.

In the following list we enumerate the residential resources intended to provide a housing service, with professional teams prepared for the sustained support of their residents. The criteria for the list is based on the number of people served by each resource, with the first resource housing the most people. The three resources are closely coordinated with the Mental Health Centers, since they are responsible for referring people to any service belonging to the SSR (Social Services Network).

#### The resources are:

- 1. Mini-residences.
- 2. Supervised apartments.
- 3. Places in supervised boarding houses.

The target user or "target" is always the same for the three types of residential resourceand the only thing that changes is the degree of supervision required by mental health professionals to meet their needs.

- Persons between 18 and 65 years of age of both sexes with severe and persistent mental illness.
- Be treated and referred to the mental health network.
- Present lack of family support or inability or overload of the family for their attentionand care.
- Have problems of autonomy and psychosocial functioning that prevent or make it difficult for them to meet their housing and support needs autonomously, and

- have difficulty remaining in an unsupervised home.
- Be in a stabilized psychopathological situation.
- Not to present behavior patterns with an excessive tendency to aggressiveness, both towards oneself and towards others.
- No addictions or serious drug or alcohol problems.
- Not have a serious physical illness that requires specialized or continuous medical care or assistance.

The financing of the mini-residences, supervised apartments and supervised pensions is privately managed with public funds, which means that the management of this economy is the responsibility of each residence, but there is public financing that allowsit to be allocated in a particular way according to its infrastructure and human, material and technological resources, etc.

#### 2.1.1 Mini-residences

The mini-residences in the Community of Madrid are organized as follows:

In the Community of Madrid there are 29 mini-residences with a total of 776 places for residents with severe mental health problems. It is a flexible and versatile residential service with 20 to 30 rooms. It offers short, transitory or indefinite stays to meet differentneeds. They offer room and board, psychosocial care and personal support to improve autonomy and support their integration, 24-hour supervision.

The professional team of the mini-residences is multidisciplinary and is made up of psychologists, nurses, social educators, social integrators, nursing assistants, administrative and cleaning staff.

#### 2.1.1 Supervised apartments

The supervised apartments in the Community of Madrid are organized as follows:

In the Community of Madrid there are 64 supervised apartments with a total of 250 places for users with severe mental health problems. The supervised apartments work linked and in coordination with the miniresidencias, since these have technical and professional staff 24 hours / 365 days a year that, in case of emergency, could make the

supervision in the apartment at the time of emergency. In addition, the technical team is contracted to visit between 10 and 20 hours per week.

This resource can accommodate short-, medium- and long-stay users to meet different needs. They are also governed by the Continuity of Care Plan.

#### They offer:

- Lodging and meals.
- Psychosocial care and personal support to improve autonomy and support

- integration.
- These do not require 24-hour supervision.
- They are managed by the social services derived from the Mental Health Centers.

The professional team of the supervised apartments is multidisciplinary and includes psychologists, nurses, social educators, social integrators, nursing assistants, administrative and cleaning staff.

#### 2.1.3 Places in supervised boarding houses

In the Community of Madrid there are 42 places in supervised boarding homes for users with serious mental health problems. The supervised places are linked to the CSM and the SSM (Mental Health Services) and to the mini-residences or other private resources or non-governmental organizations that take care of their professional and logistical management.

Through the payment of places in boarding houses for people who rent their rooms, theaim is to provide decent accommodation and cover the basic needs of mentally ill people with a good level of autonomy but without family support or economic resources, in an attempt to avoid marginalization processes.

The professional team of the supervised boarding houses is multidisciplinary, since they are linked to the mini-residences and are made up of psychologists, nurses, social educators, social integrators, nursing assistants, administrative and cleaning staff.

• Support service for the social reintegration of people with severe mental illness in a situation of social exclusion.

In 2020, 3,384,414 euros were allocated to cover, during the period 2020 - 2023, supportfor 130 homeless people with severe mental illness. Independent living is supported from different services:

- The Department of Social Policies, Families, Equality and Birth of the Community of Madrid has five apartments in the city of Madrid, which have a capacity of 20 places for this target.
- These accommodations are managed by the entity awarded the contract, in addition to another ten places in residential accommodation in boarding houses or hostels to facilitate their social reintegration. The premises for the coordination of the service will also be provided by the entity.
- They maintain a multidisciplinary team composed of social workers, integrators, psychologists, nurses and social educators.

#### 2.2. Other resources of the Mental Health Social Services Network

We recognize the importance of other support resources for independent living aimed at providing a service of accompaniment, prevention and recovery of people with mental

health problems, with the aim of increasing the capabilities of personal and social management to lead an independent life. The listing criteria is subject to the hierarchy established by the CSM (Mental Health Center) for the person to carry out a process of recovery and psychosocial rehabilitation until complete autonomy is achieved.

#### 1.- CSM (Mental Health Center):

Mental Health Centers in the Community of Madrid are specialized medical care institutions dedicated to the evaluation, diagnosis, treatment and follow-up of people with mental disorders and mental health problems. Their main functions include:

- Evaluation and diagnosis: Mental Health Centers conduct comprehensive evaluations to determine the mental health status of patients. This involves clinical interviews, psychological testing and psychiatric evaluations to establish an accurate diagnosis.
- Treatment: They provide a variety of treatment options, which may include individual therapy, group therapy, family therapy, psychopharmacology (administration of psychiatric medications) and other specific therapies to address mental disorders such as depression, anxiety, schizophrenia, among others.
- Mental health prevention and promotion: In addition to treatment, Mental Health
  Centers can offer mental health prevention and promotion programs to help
  prevent mental health problems and improve psychological well-being in the
  community.
- Psychosocial rehabilitation: Helps patients reintegrate into society and regain daily living skills, which may include job training, education and social support.
- Family support: They provide support to families of people with mental disorders, offering guidance and education on how to manage and support their loved ones.
- Coordination of care: Mental Health Centers can collaborate with other health care services, general hospitals and social services to ensure comprehensive care for their patients.
- Research and training: Some Mental Health Centers also engage in research in the field of mental health and offer education and training programs for mental health professionals.
- Crisis Care: Provide emergency care for persons in mental crisis, including assessment of danger to self or others and referral to emergency services if necessary.
- Long-term follow-up: They continuously follow patients over time to ensure that they are receiving appropriate treatment and to adjust the plan of care as needed.

#### 2.- CD (Day Center):

Mental Health Day Care Centers in the Community of Madrid offer a variety of activities and methodological approaches designed to address the needs of theirusers. Some of the common activities and approaches may include:

Individual and group therapy: They offer individual and group therapy sessions to address specific mental health issues, improve coping skills and promote peersupport.

- Occupational and recreational activities: Centers may offer occupational and recreational activities such as art, music, sports, cooking and gardening to promote well-being and social inclusion.
- Psychosocial support: They provide support in daily living, social skills acquisition and personal autonomy, which may include planning daily activities and stress management.
- Mental illness education: Provides educational information about mental illness and strategies to manage symptoms and prevent relapse.
- Family support: They offer support and guidance to the families of users to help them understand and support their loved ones.
- Access to health services: Facilitate access to medical and psychiatric services, including the administration of medication if necessary.
- Social support network: They encourage the construction of a social support network among users, promoting active participation in the community.

#### 3.- CAD (Center of Attention to Drug Addiction):

The Integral Care Centers for Drug Addicts (CAID) are health centers distributed throughout the Community of Madrid. These centers, by means of a Clinical Management Project, organize health and social rehabilitation activities:

- Clinical psychologyNursing
- Psychiatric Medical
- Social work

#### The essential services are:

- Information and Orientation Service
- Assessment, Diagnosis and Therapeutic Plan Service Therapeutic Follow-up and Control Service
- Family Care Service

These outpatient centers have the possibility of temporarily referring patients to other services and residential centers within the Community of Madrid's Network of Care for Drug Addicts, where they will be attended in order to complete the continuity of care.

#### 4.- CAEF (Family Assistance Center):

The Family Support and Meeting Centers of the Community of Madrid (CAEF) offer care to each and every one of the family members through various specialized services that are free, personalized and confidential. They are cared for by multidisciplinary teams made up of psychologists, lawyers, social workers and educators with training and experience in

working with families.

Access is direct by telephone appointment.

Here is a brief explanation of what is done in these centers:

- Emotional and psychological support: Family Care Centers offer a safe space for families to express their concerns and emotions. They provide emotional support and psychological counseling to help families cope with stress, crisis or conflict situations.
- Guidance and counseling: Helping families understand and address their specific challenges, whether they are related to parenting, family conflict, financial difficulties or mental health issues
- Education and training: They offer workshops and training programs to improve parenting skills, family communication, conflict resolution and other skills necessary for family life.
- Referral to specialized services: If necessary, Family Care Centers can refer families to other specialized services in the community, such as mental health services, social services or legal advice.
- Promotion of family coexistence: Promote an environment conducive to healthy family coexistence, providing guidelines and strategies to strengthenfamily ties and create a harmonious home environment.
- Crisis support: In cases of family crisis, such as domestic violence or job loss, these centers provide immediate support and resources to help families overcome difficulties.
- Access to community resources: Inform families about resources and services available in the community that may be useful for their particular situation, such as social assistance programs, support groups or child care services.

#### 5.- CRPS (Psychosocial Rehabilitation Center):

A Psychosocial Rehabilitation Center (CRPS) in the mental health field is a specialized institution that provides rehabilitation and support services to peoplesuffering from severe and persistent mental disorders. The main goal of these centers is to help people recover and improve their quality of life by providing them with the tools and support needed to live independently and participate fullyin the community. Here is a more detailed explanation of what a Psychosocial Rehabilitation Center entails:

- Comprehensive Rehabilitation: CRPS focuses on comprehensive rehabilitation, which means that it addresses not only the medical aspects ofmental illness, but also the psychological, social and occupational aspects. The goal is to help people regain or improve their skills and functioning in allthese aspects of life.
- Individualized Planning: Each person who comes to CRPS receives an individualized rehabilitation plan that is tailored to his or her specific needs and goals. This plan is developed in collaboration with the individual and hisor her

treatment team.

- Social and Life Skills: CRPS offers training and support to develop social skills, communication skills, problem-solving skills and independent living skills. This may include teaching how to manage medication, time management and performing daily activities.
- Occupational Activities and Education: Provide occupational and educational activity programs that help people acquire new skills, participatein meaningful activities and improve their self-esteem.
- Job Placement Support: Many CRPS are dedicated to helping people find and maintain employment by providing job search training, careercounseling and onthe-job support.
- Emotional and Psychosocial Support: They offer emotional and psychosocial support through individual therapy, group therapy and crisis support to help people manage the symptoms of their mental disorders and cope with difficult situations.
- Promoting Autonomy: Promote the independence and autonomy of individuals, encouraging them to make decisions about their own treatmentand daily life.
- Community Participation: CRPS helps people reintegrate into the community, facilitating participation in social, cultural and recreational activities outside the center.
- Evaluation and Follow-up: They conduct periodic evaluations to measure each individual's progress and adjust their rehabilitation plans as needed.

#### 6.- CRL (Labor Rehabilitation Center):

Occupational Rehabilitation Centers (CRL) are a specific resource of specialized social services, intended for people with severe mental illness to help them recover or acquire the work habits and skills necessary to access the world of work and support their integration and maintenance in it. Its attention capacity is around 50 users.

Some Center are financed for the 40% by the European Social Found Plus.

#### 3. LEGISLATION

- Spanish Constitution of 1978.

"The Spanish Constitution of 1978 is the center of the political system and the legalsystem of Spain. It establishes the other norms, the fundamental rights and public freedoms, the principles of action of the public authorities and the institutional and territorial organization of the State. The higher values of Spain, as a social and democratic State under the rule of law, are freedom, justice, equality and political pluralism." - La Moncloa, official website of the President of the Government and the Council of Ministers.

- Law 14/1986, of April 25, 1986, General Health Law.

#### Article 10.

Every person has the following rights with respect to the various public health administrations:

- 1. To respect his or her personality, human dignity and privacy, without being discriminated against on the basis of racial or ethnic origin, gender and sexual orientation, disability or any other personal or social circumstance.
- 2. To information on the health services that can be accessed and on the requirements necessary for their use. The information should be provided in appropriate formats, following the rules established by the principle of design for all, so that they are accessible and understandable to persons with disabilities.
- 3. To the confidentiality of all information related to their process and their stay in public and private health institutions that collaborate with the public system.
- 4. To be advised if the prognostic, diagnostic and therapeutic procedures applied may be used on the basis of a teaching or research project, which, in no case, mayentail an additional danger to his/her health. In any case, the prior written authorization of the patient and the acceptance by the physician and the Management of the corresponding Health Center shall be essential.
- 7. You will be assigned a physician, whose name will be made known to you, who will be your main interlocutor with the care team. In case of absence, another physician of the team will assume this responsibility.
- 10. To participate, through community institutions, in health activities, under the terms established in this Law and in the provisions that develop it.
  - 11. Use the complaint and suggestion channels within the established deadlines. Ineither case, you must receive a written response within the deadlines established by law.
  - 12. To elect the physician and other collegiate health workers in accordance with the conditions set forth in this Law, in the provisions issued for its development and those regulating health work in the Health Centers.
  - 13. To obtain the medicines and sanitary products considered necessary to promote, preserve or restore health, under the terms established by the regulations of the State Administration.
  - 14. Respecting the economic regime of each health service, the rights

contemplated in paragraphs 1, 3, 4, 5, 6, 7, 9 and 11 of this article shall also be exercised with respect to private health services.

- <u>Law 39/2006, of December 14, 2006, on the Promotion of Personal Autonomy</u> and Care for Dependent Persons.

This Law regulates the basic conditions for the promotion of personal autonomy and care for dependent persons through the creation of a System for Autonomy and Care for Dependency (SAAD), with the collaboration and participation of all Public Administrations.

#### Article 15. Catalog of services.

- 1. The Service Catalog includes the social services for the promotion of personalautonomy and care for dependency, under the terms provided for in this chapter:
  - a. Services for the prevention of situations of dependency and those for the promotion of personal autonomy.
  - b. Teleassistance Service.
  - c. Home help service:
    - (i) Attention to household needs.
    - (ii) Personal care.
    - d. Day and Night Center Service.
    - e. Residential Care Service:
- (ii) Care center for people in a situation of dependency, according to the different types of disability.
  - 2. The services established in paragraph 1 are regulated without prejudice to the provisions of Article 14 of Law 16/2003, of May 28, on Cohesion and Quality of the National Health System.
    - <u>Law 16/2003</u>, of May 28, 2003, on the cohesion and quality of the National HealthSystem.

#### Article 14. Provision of social and health care.

1. Socio-health care includes the care of those patients, generally chronically ill, whodue to their special characteristics can benefit from the simultaneous and synergic action of health and social

services to increase their autonomy, alleviate their limitations or suffering and facilitate their recovery. social reintegration.

- 2. In the health field, social and health care shall be carried out at the levels of caredetermined by each autonomous community and shall include in any case:
- a) Long-term medical care.
- b) Medical assistance for convalescence.
- c) Rehabilitation in patients with recoverable functional deficit.
- 3. The continuity of the service will be guaranteed by the health and social servicesthrough adequate coordination between the corresponding public administrations.
- <u>Decree 122/1997, of October 2, 1997,</u> which establishes the Basic Legal Regime of the Public Service of Social Care, Psychosocial Rehabilitation and Community Support for Persons Affected by Serious and Chronic Mental Illnesses, in the different Specialized Centers of Social Services.

Chapter two: Centers and Benefits

Article 5. Types of centers: Definition and benefits.

- a) Mini-Residences: These are residential centers for persons affected by serious or chronic mental illnesses and with deterioration of their personal and social autonomy. They provide, on a temporary or indefinite basis: lodging, maintenance, care, personal and social support, rehabilitation and support for community integration, to the aforementioned persons who do not have family and social support and/or who, due to their degree of psychosocial deterioration, require the services of this type of residential center.
- b) Supervised Apartments: These are a community resource for housing and socialsupport located in apartments where people affected by serious and chronic mentalillnesses live, with a sufficient level of autonomy and who do not have family support. They will offer, on a temporary or indefinite basis depending on the needs of each case: accommodation, personal and social support, support for rehabilitation and integration, as well as flexible and continuous supervision.
- c) Other residential facilities: These include those other residential facilities or resources that may be established to offer housing and social support services to persons with chronic mental illnesses and difficulties of psychosocial functioning and integration who need it

due to their social and/or social condition. family problems. some type of residential support.

#### Article 7. Form of access.

- 1. Users must be attended by one of the public Mental Health Services dependent on the Community of Madrid. The form of access to the different centers integrated in the Public Service regulated herein, shall be made by means of a proposal from the Mental Health Service responsible for the psychiatric care of each user, by means of a reasoned report justifying the need for social assistance, rehabilitation and/or residential care in any of the aforementioned centers or facilities. In the case of the patient, rehabilitation and/or residential care in any of the aforementioned centers or facilities.
- 2. The Ministry of Health and Social Services will establish the specific criteria for access and the profile to be met by users in the different types of centers or resources. It will also determine the coordination mechanisms with the Mental Health Services for the selection, evaluation and referral of users and for their follow-up.

#### Article 9. Fees, public prices and rates.

The Ministry of Health and Social Services may establish a system of user participation in the cost of the care received in any of the types of centers included in the Public Function, in accordance with the provisions of Law 1/1992, of March 12, 1992, on Public Order, Rates and Prices of the Community of Madrid.

#### Article 10. Rights and duties of the users.

- 1. The provision of the Public Service regulated in this Decree shall guarantee respect for the fundamental rights of the individual and those mentioned in Law 8/1990, of October 10, Regulating the Inspection and Control of Social Action Centers and Services.
  - Law 1/1992, of March 12, 1992, Tariffs and Public Prices of the Community of Madrid.

#### Article 20. Payment.

1. Fees shall be paid in cash, unless the use of stamped tickets is provided for in the regulations. Payment of fees by means of stamped tickets issued by other public administrations shall not be allowed.

2. The Departments, autonomous bodies and public entities referred

to in Article 19.2 have the power to authorize, upon request of the interested parties, deferments or instalments in the payment of fees. If the debts have been ordered as a matter of urgency, the Ministry of Finance shall be competent.

#### Mental Health Action Plan 2022-2024.

"Within the framework of the 2003 Cohesion and Quality Law, the Ministry of Health(MS) in collaboration with the autonomous administrations, developed the first Mental Health Strategy of the National Health System (NHS) which was published in 2006 and subsequently updated for the period 2009-20132, serving as a tool andreference for the deployment of programs and actions that have been developed in the National Health System for the approach and care of mental health."

The strategic lines of the Mental Health Action Plan for the period 2022-2024are:

Autonomy and rights. person-centered care.

Promotion of the mental health of the population and prevention of mental health problems.

mental health problems.

Prevention, early detection and attention to suicidal behavior.

#### **CONCLUSION**

The Regional Ministry of Health and the Regional Ministry of Social Policies, Families, Equality and Birth, coordinate in the promotion of personal autonomy and independent living skills for people with mental health problems. The Continuity of Care Plan links both Departments through the Mental Health Centers, which belong to the former, and the residential and independent living support resources which belong to the latter. Multidisciplinary teams (psychologists, social workers, occupational therapists, etc.) are coordinated in all the devices and residential resources, working towards the achievement of personal, social and vital objectives.

In the Community of Madrid we have residential resources, which are establishments that provide housing and specialized care to people in situations of vulnerability, dependence or disability, with the aim of improving their quality of life and guaranteeingtheir well-being.

There are a total of 1088 public residential places for the promotion of autonomy and independent living. These places are distributed among the following residential resources:

- Mini-residences.
- Supervised apartments.
- Supervised pensions.

The aforementioned legislation justifies the coordination between the Ministries, the management of the residential resources, their financing, the rights of the persons assisted, and the duties of the social and health services in order to guarantee optimal care adjusted to the autonomy needs of the persons with mental health problems assisted.

#### **SUMMARY-SHEET**

RESIDENTIAL RESOURCE	NO. SEATS	ATT. PROFESSIONAL IN HOURS
Miniresidency	29 mini-residences 776 seats	24 hours of professional attention by a multidisciplinary team.
Supervised apartments	64 floors 250 seats	Between 10 and 20 hours per week of professional care by a multidisciplinary team. They are linked to the miniresidences.
Supervised pensions	42 pensions 42 seats	Between 10 and 20 hours per week of professional care by a multidisciplinary team. They are linked to the miniresidences.
Social reintegration supportservice	5 floors 20 seats	It depends on the supervised apartment and the professional teams in charge of social and labor reintegration.

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#### I.B – SERVICES PROVIDED IN THE COMMUNITY OF LISBOA

#### RESPONSES TO THE PROMOTION OF INDEPENDENT LIVING IN MENTAL HEALTH

#### 1. Introduction

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#### 1. Introduction

#### 1.1. Current Health System in the Country

From the 1960s onwards, the foundations of the community mental health policy were laid in Portugal, appearing in 1963 the 1<sup>st</sup> Mental Health Law that establishes the general principles of mental health policy and the guiding principles for the decentralization of services, through the creation of mental health centers and the connection to primary health care.

However, from the 1970s onwards, difficulties began to arise in the compatibility between the organizational model and the new organic models of the Ministry of Health and in 1992 the integration of mental health in general health services began and mental health centers were extinguished, passing the provision of mental health care to the domain of general, central and district hospitals. This integration did not safeguard, however, the creation of necessary conditions, by not having been attributed financial and administrative autonomy to psychiatry services and having been created obstacles to the development of community services, which brought negative consequences (Santos and Pedrosa, 2016).

The reformulation of mental health policy became urgent, and the new Mental Health Law, in 1998, formalized the need to create a diversified network of responses with articulation between the ministries of Health and Social Security, and community social organizations. This law establishes the general principles of mental health policy, guidelines for the organization of services and regulates compulsive internment. It defines as general principles (Article 3<sup>rd</sup>): "the provision of mental health care at the community level; in the least restrictive environment possible; hospitalizations in general hospitals; and ensures psychosocial rehabilitation, through the provision of care in "residential structures, day centers and professional training and reintegration units, inserted in the community and adapted to the specific degree of autonomy."

This legislation allowed the viability of psychosocial rehabilitation programs in Portugal, with the Joint Order No. 407/98, contributing to important advances with regard to the integration of people with mental illness in the community. However, despite these advances, the coverage of the national territory remained very incomplete.

In 2006 the Government's Health Policy provided for the implementation of the National Network of Continued Integrated Care (RNCCI). This integrated intervention model was intended to be a new intermediate level of health care and social support, between community-based and inpatient care. This Network is in 2010 extended to the area of mental health (Decree-Law No. 8/2010) and there is an attempt to deepen the experience of the Joint Order No. 407/98, with the reformulation and creation of new types of units and expansion of promoting entities, from the social sector to the

public and private profit-making sectors. Subsequently, the coordination and care teams were established, as well as the conditions of organization and operation of the units.

The RNCCI legislation for mental health has undergone several legislative changes, to this day, at the level of coordination of units and integrated long-term care teams, as well as the review of the conditions of installation, organization, operation and capacity of the teams

The implementation of the RNCCI continues to be incipient and does not cover the national territory, having the legislation on pilot-experiments started in 2011 and operated between 2017 and 2020 the aforementioned units and teams, but with great limitations, having been carried out some reconversions of existing social responses, but few new units were created.

Currently, responses created under the Joint Order No. 407/98 and the RNCCI for Mental Health coexist, which we will describe throughout this report.

More recently, Decree-Law No. 113/2021 established the general principles and rules of organization and functioning of mental health services. The model of government becomes dependent on national and regional coordination structures; national, regional and local advisory bodies representing the community are established; and the organization of mental health services at regional and local levels have a strengthening of sectorization and deployment in the community, with Community Mental Health Teams; and there is a strengthening of the articulation with other areas of care (Primary Health Care, RNCCI).

Recently the new Mental Health Law – Law No. 35/2023 of July 21<sup>st</sup> was published, which focuses on the definition, foundations and objectives of mental health policy; enshrines the rights and duties of people in need of mental health care; and regulates the restrictions of these rights and the guarantees of the protection of freedom and autonomy.

Recent legal frameworks take into account international strategic instruments, including the Convention on the Rights of Persons with Disabilities adopted by the United Nations.

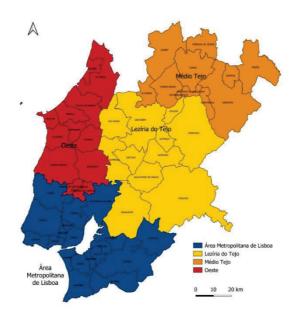
Finally, it should be noted that all current legislation is applied at national level, not varying territorially.

#### 1.2. Characterization of the Territory

This report will cover the mental health services and responses of the Lisbon Metropolitan Area, which is part of the Lisboa e Vale do Tejo (Lisbon and Tagus Valley) Regional Health Area (ARS LVT).

The Lisbon Metropolitan Area (AML) had, in 2021, 2.870.208 inhabitants, and this number increased by 1.7%, compared to the last census of 2011 (48.332 more inhabitants). The territory of the AML comprises 18 municipalities and 118 parishes.

In the distribution of regional health areas, the Regional Health Area of Lisboa e Vale do Tejo (Lisbon and Tagus Valley) is one of the five administrations, with an area of 11.633 km<sup>2</sup> and about 3.698.201 inhabitants - an increase of 0.07% compared to 2011 - which corresponds to 36% of the Portuguese population. It is the westernmost border of Portugal and the European continent and encompasses 52 municipalities and 355 parishes.



Map of the Regional Health Area of Lisboa e Vale do Tejo (Lisbon and Tagus Valley)

#### 1.3. Incidence of mental illness in the national territory and in the ARS LVT

Data from the 1<sup>st</sup> national epidemiological study of mental health, released in 2013, reveal that more than a fifth of the people interviewed had a psychiatric disorder in the 12 months prior to the study, and the estimated prevalence of occurrence of at least one psychiatric disorder during life was 42.7% (Almeida & Xavier).

According to the same study, the prevalence of psychiatric disorders in Portugal was in 2013, the second highest in Europe of 22.9% (one fifth of the Portuguese), dominating anxiety disorders (16.5%) followed by mood disorders (7.9%). It also reveals that almost 65% of people with a psychiatric disorder have not had any treatment in the previous 12 months and that even in the most severe cases there are more than a third of them that have not had access to treatment.

The report "Portugal - Mental Health in Numbers" (2015) reveals that mental and behavioural disorders maintain a significant weight in the total years of healthy life lost by the Portuguese, with a rate of 11.75%.

According to OCDE (Organization for Economic Cooperation and Development) data from 2018, Portugal is the EU country with the highest prevalence of psychological disorders, which affect

almost 25% of the population with over 16 years of age, and in the European Union is the 5th country where more people suffer from Anxiety and Depression.

In 2019, mental disorders constituted in Portugal the fourth main type of pathology (23.2%) in terms of Global Burden of Diseases (National Observatory for the Fight against Poverty, EAPN).

According to data from the Portuguese Society of Psychiatry and Mental Health, about 4% of the adult population has a severe mental disorder, 11.6% a disorder of moderate severity and 7.3% a disorder of mild severity.

Finally, more recently the COVID-19 pandemic has reinforced the burden of mental illness, according to data on the impact of COVID-19 on the mental health of the general population, high values in the development of mental health problems stand out, such as: 33.7% of psychological distress, 27% of moderate or severe anxiety, 26.5% of post-traumatic stress, 26.4% for moderate to severe depression and 25.2% of *Burnout*. For the most affected groups, there is a higher incidence of symptoms of moderate to severe psychological suffering in: women, young adults aged 18 to 29, the unemployed and individuals with lower income (SPPSM and INSA, 2023).

In the Lisboa e Vale do Tejo (Lisbon and Tagus Valley) region, data from 2015 reveal that the mortality rate associated with suicide, alcohol consumption and psychotropic drugs was the third highest in Portugal (Carvalho et. al, 2016).

According to 2020 data, there are 200.115 children and adults diagnosed with mental disorders in the ARS LVT, for a total of 3.496.064 across the continental territory (INE, 2022).

At ARS LVT there are currently 39 responses for people with mental illness and/or psychosocial disability, including residential, occupational and home support staff with an estimated maximum capacity of 607 places. Of these 607 places, it is estimated that 541 are occupied, corresponding to an occupancy rate of 89% (Social Charter, 2021).

#### 2. Residential Services for People with Mental Illness

In Portugal, residential responses are not public, and there is a shared financing model between the State, through the financing of the ministries of Health and Social Security, and the beneficiary of the service, which contributes according to the income and expenses of the household. In turn, the State delegates the implementation and management of these responses to community entities, social (IPSS, Religious Orders and others). Hospitals and psychiatric services develop other residential responses within the scope of their services, however, they will not be considered in this report because they do not have a legal framework and are mostly implemented within hospitals.

Thus, in the region of Lisboa e Vale do Tejo (Lisbon and Tagus Valley) there are several typologies of mental health responses or services that promote the independent life of people with mental illness. They will be listed below, according to the periodicity and/or need for supervision and

technical support, starting from the answers that provide care to people with a higher degree of dependence, to the answers or support services to people with a higher level of autonomy.

The residential structures will be described taking into account the two legal frameworks, still ruling, and already mentioned above (Joint Order No. 407/98 and the RNCCI of mental health).

The intervention model of all these responses is the psychosocial rehabilitation model, being an approach in which its main objective is to complement the drug treatment, to enable the person to achieve their maximum in terms of personal, social, professional and family functioning, in the least restrictive way possible (Ferreira, 2013; Farm, 2009).

In the ARS LVT there are in the various typologies of residential responses for people with mental illness (UVAP, UVAU and UPRO, RAMa, RAMo, RTA, RA) 159 places, of which 145 are occupied, making an occupancy rate of 91% (Social Charter, 2021).

#### 2.1. Residential services under Joint Order No. 407/98

Under the Mental Health Law No. 36/98, of July 24<sup>th</sup>, which establishes the general principles of mental health policy for people with mental disorders, psychosocial rehabilitation responses were created regulated by Joint Order No. 407/98, of June 18<sup>th</sup>, which establishes the guidelines for the articulated intervention of health (Ministry of Health) and social action (Ministry of Social Security) and the creation of residential responses directed to people with mental or psychiatric illness, within the scope of social support.

These residential responses constitute short- to long-term housing alternatives, they should be inserted in a common residential community, whenever possible in a residential building, and primarily in urban and suburban environments. It must be located in a residential area with basic infrastructure and served by a public transport network.

They are intended for young people and adults with severe stabilized psychiatric illness, which determines personal disorganization, difficulties of family and social insertion, and/or impossibility of autonomously accessing or maintaining a housing space with safety and stability (Guidelines regulating the articulated intervention of social support of continuing health care directed to people in situations of dependence, 1998).

There are as typologies units of supported life, units of protected life and units of Autonomous Life. Admission to these units is based on the situation of psychic dependence, evaluated by the Mental Health Team, and the referral can currently be made by oneself, family, or professionals in the social or health area.

Integration in these responses is voluntary and implies acceptance of one's own. The length of stay, depending on the case, may be short, medium or long duration (this duration may be indeterminate).

These responses are developed and managed by the social sector, namely Private Institutions of Social Solidarity (IPSS), which are non-profit entities constituted on the initiative of private individuals and that emerge from civil society.

They are financed by the Ministry of Labour, Solidarity and Social Security, through atypical cooperation agreements that translate into amounts not fixed but established after case-by-case analysis. The beneficiary of this service also contributes a percentage of the per capita income of the household, calculated according to the income and expenses of his household.

There are currently 14 Life Units (11 protected and 3 autonomous) in the Lisboa e Vale do Tejo (Lisbon and Tagus Valley) Region, being located in the Lisbon Metropolitan Area) and responding to a total of 81 people with severe mental illness.

# a) Supported Life Unit (UVAP)

The ARS LVT currently has no Supported Life Unit, and the only existing unit has been converted into a Maximum Support Residence, which will be described later.

# b) Protected Life Unit (UPRO)

The ARS LVT has 11 Protected Living Units, with capacity for 4 to 7 residents with severe mental illness (making a total of 64 places).

This is a housing structure intended for the training of autonomy of adult people, with severe mental illness and chronic evolution, with no other residential alternative or that even existing seems as unfeasible. They should be clinically stabilized and have potential for development.

This response offers accommodation and food; integration of the user in occupational programs, training and/or employment actions; autonomy training in the various activities of daily living; and community living. It is intended to learn organizing habits, enable group coexistence, allow a close connection to the community, and avoid institutionalization.

It works every day, 24 hours a day, and a night stay and on non-working days must be guaranteed. Integrated in this residential response is a multidisciplinary team constituted on a referential basis by: social worker, psychologist, occupational therapist, home helpers, auxiliary and administrative workers.

#### c) Autonomous Living Unit (UVAU)

The ARS LVT has 3 autonomous living units, with capacity for 3 to 7 residents with severe mental illness (making a total of 17 seats in the ARS LVT).

This response is intended for adults, with good autonomy capacities, clinically stable and without a satisfactory residential alternative.

This residential unit offers accommodation and meal services, contact with the community and integration programmes in vocational training and/or normal or supported employment. It is intended to ensure the individualization and stability of users in a normalized life, both in the relational and labour aspects.

The multidisciplinary team integrated in this response is constituted in a basic reference by: social worker and auxiliary worker. This answer works every day, 24 hours a day, however, it only has part-time supervision.

#### 2.2. Residential services of the National Netword of Continued Integrated Care for Mental Health

From 2010 a new legislation appears framed in the National Netword of Continued Integrated Care, regulated in Portuguese legislation through: (1) Decree-Law No. 101/2006, of June 6<sup>th</sup>, which creates the National Netword of Continued Integrated Care (RNCCI) and defines the different typologies, models of access, admission and mobility in the RNCCI, as well as its organization; (2) Decree-Law No. 8/2010, of January 8<sup>th</sup>, which creates the units and teams of integrated long-term care of mental health (CCISM) and defines the target population, presents and characterizes the set of units and specific mental health teams, including residential and occupational units, defining the objectives, organization and coordination thereof; (3) Legislative Order No. 14-A/2015, of July 29<sup>th</sup>, which defines the forms of co-payment by social security by CCISM services; (4) most recent legislative amendment with Ordinance No. 311/2021, of December 20<sup>th</sup>, which creates national, regional and local coordination of CCISM units and teams, defining their organisations and operations.

The RNCCI for mental health provides for the creation of residential units, in analogy to those created by the Joint Order No. 407/98, although with changes in the teams, financing model, organizational structure, functional program of the facilities of the Units, duration of the intervention, among others. It introduces new typologies: Autonomy Training Residency and Home Support Teams, as well as answers for childhood and adolescence, which we will not explain in this report that we limit to the adult population.

The residential structures created or reconverted, within the scope of the RNCCI for mental health, present different levels of intensity, are preferably located in the community and ensure the provision of medical and social services. They have as typologies: maximum support residences, moderate support residences, autonomy training residences and autonomous mental health residences.

They are aimed at people with psychosocial disability and need for integrated long-term mental health care who: are living in the community; are discharged from the acute units of psychiatric hospitals, from psychiatric institutions in the social sector or from psychiatric departments and services of hospitals; are discharged from long-term care units, public or private; or are referred by Local Mental Health Services (SLSM).

Admission to the units is determined by the coordinating team, on a proposal from the SLSM or the psychiatric institutions of the social sector. The users are referred and evaluated by the Local Mental Health Services (SLSM), to prove the criteria, and integration or referral to respond more appropriately to the needs, and this process of referral and allocation to the units is carried out through the RNCCI. There will have to be an acceptance on the part of the self, having the integration in these answers a voluntary character.

The maximum period of stay in the residences is 12 consecutive months and may be extended upon proposal presented by the technical team and favourable opinion of the respective Regional Coordination Team.

The RAMa and RAMo units allow for periods of up to 30 consecutive days, a maximum of 90 days per year, the admission of people with family support, with a view to the rest of the main caregiver, provided that it is proven that they meet the admission criteria.

These responses are administered and managed (in conjunction with the National, Regional and Local Mental Health Coordination) by Private Institutions of Social Solidarity (IPSS) or by other public or private entities.

Regarding the financing model, this response is co-financed by the Ministry of Health, through an amount fixed per day, per user, regulated by law. In addition, the beneficiary of this service pays, according to the income of the household and the number of members that constitute it. When the user is not able to support the full amount of the contribution related to social support services, the Ministry of Labor, Solidarity and Social Security pays the difference.

There are in the Lisboa e Vale do Tejo (Lisbon and Tagus Valley) Region, in the Lisbon Metropolitan Area, 7 Residential Units (1 maximum support, 1 moderate support, 3 autonomy training and 2 autonomous), responding to 78 people with severe mental illness.

#### a) Maximum Support Residence (RAMa)

There is in ARS LVT 1 Maximum Support Residence (RAMa), with capacity for 24 users with severe mental illness.

It is a residential structure, located in the community. To reside in this answer, the person must present a high degree of psychosocial disability (marked cognitive and functional limitations) derived from psychiatric conditions and that, therefore, needs support in hygiene, personal care, food and in the management of money and medication. However, it should be clinically stabilized.

Its purpose is to provide care that prevents and delays the worsening of the situation of dependence

In coordination with community services, the team develops daily psychosocial rehabilitation activities, support in performing daily tasks, psychosocial support and awareness actions and training for family members and other informal caregivers, provide access to general health care and the specialty of psychiatry, such as daily nursing care as needed, management and administration of therapeutic means, food and hygiene, treatment of clothing, conviviality and leisure, and contact with the community.

The multidisciplinary team of this response consists of nursing professionals specialized in mental health and psychiatry, social workers, psychosocial rehabilitation technicians, monitors and direct-action assistants. These services take place every day, 24 hours a day, with 24-hour supervision.

#### b) Moderate Support Residence (RAMo)

There is 1 moderate-support residence at ARS LVT, with capacity for 10 residents with severe mental illness.

The target population is people with a moderate degree of psychosocial disability, clinically stable, without adequate family or social support. These people should have retained their instrumental functionality, but still need regular supervision in the basic and instrumental activities of daily living.

These residences aim to provide care that allows the maintenance and development of skills, providing better quality of life and promoting socio-occupational integration.

The team develops daily activities of psychosocial rehabilitation, offers support in carrying out the daily activities of the user, carries out actions of sensitization of family members and other informal caregivers, facilitates and mediates the access of the user to general health care, nursing and specialized psychiatry, assists in the management of medication, food, hygiene care, clothing treatment, enabling conviviality, leisure and contact with the community.

The multidisciplinary team of this response consists of nursing professionals specialized in mental health and psychiatry, social workers, clinical psychologists, psychosocial rehabilitation technicians, monitors and direct-action assistants. These services take place every day, 24 hours a day.

#### c) Autonomy Training Residency (RTA)

The ARS LVT has 3 autonomy training residences, with a maximum capacity for 12 residents with severe mental illness (making a total of 31 seats). The capacity of the autonomy training residences is 12 seats.

It is a residential unit, preferably located in the community, which allows to support people, with reduced to moderate degree of psychosocial disability, clinically stable, with basic functionality conserved, but who, nevertheless, need supervision in their daily activities.

Its purpose is the social and family reintegration of people with psychosocial disabilities, preparing them for the return home. This team develops daily activities of psychosocial rehabilitation for the user, actions of sensitization and training of family members and informal caregivers, facilitates and mediates access to general health care, nursing and psychiatric specialty, works the autonomy and assists the management of medication, food, hygiene, care with clothing, and provides conviviality, leisure and contact with the community.

This response relies on a multidisciplinary team consisting of nursing professionals specialized in mental health and psychiatry, social workers, clinical psychologists, psychosocial rehabilitation technicians, monitors and direct-action assistants. It works every day, 24 hours a day.

# d) Autonomous Residence (RA)

In ARS LVT there are 2 autonomous residences, with capacity for 7 residents with severe mental illness (making a total of 13 places). The maximum capacity of the autonomous residences is seven seats.

It is a residential structure that is intended for people, with a reduced degree of psychosocial disability, clinically stable, without adequate family or social support, who have their basic and instrumental functionality preserved, but who need regular supervision of daily activities.

Its purpose is to provide residential support with a view to integration into socialization activities and professional training or employment, the improvement of quality of life and greater social participation.

The team offers support in the planning of activities of daily living, psychosocial support, support in the integration in professional and socio-professional activities, facilitate and mediate access to general health care and psychiatric specialty, support in the management of medication, food and provide activities of conviviality, leisure and contact with the community.

It has a multidisciplinary team consisting of social workers or psychologists and assistants of management services. It works every day, 24 hours a day, with reduced supervision.

# 3. Home Services

Parallel to these residential structures, there is also the possibility of home support, through home support teams (RNCCI EAD) and community mental health teams.

Below we will describe the different responses existing in the Lisbon Metropolitan Area.

# Home Support Team for Continued Integrated Mental Health Care (EAD)

Created under the National Netword of Continued Integrated Care for mental health, there are in ARS LVT, 2 home support teams, with a maximum capacity for 8 daily visits, and that support people with mental illness or psychosocial dysfunction, clinically stabilized, with residence in the community, in their own or family home.

They are multidisciplinary teams that provide services, from the promotion of autonomy in the basic and instrumental activities of daily living; facilitating access to occupational, social and leisure activities; awareness, involvement and training of family members and informal caregivers; mediation in access to general health care and the specialty of psychiatry; and medication supervision and management.

These functions are developed 7 days a week, on weekdays. Unlike the other units, there is no maximum, regulated support period for responses of this nature.

#### Community Mental Health Team (ECSM)

Hospitals and psychiatry services have created, over the years, Community Mental Health Teams that provide health care in the community, these services being public and free. These teams are expected to expand in the coming years under the Recovery and Resilience Programme (PRR).

At ARS LVT there are 8 Community Mental Health Teams (ECSM) that are aimed at adults with mental illness who need essential global mental health care, both outpatient and inpatient.

The ECSM-PA ensures a set of services and interventions namely: external consultation by the various professionals; psychotherapies and individual psychological accompaniment; group therapies and interventions; home visit; articulation with other community structures; articulation with Primary Health Care; social intervention; user-centred community interventions; structured interventions, namely: psychoeducational interventions, neuropsychological interventions, body mediation therapies and occupational therapy.

#### 4. Other Services

In addition to residential and home responses, there are also occupational responses, employment support measures and projects such as: *Housing First apartments* - for homeless people with mental illness and Independent Living Support Centres (CAVI),

Below we will describe the different responses existing in the Lisbon Metropolitan Area.

# a) Socio-Occupational Forum (FSO)

In the Regional Health Area of Lisboa e Vale do Tejo (Lisbon and Tagus Valley) there are 16 Socio-Occupational Forums (16 in the AML and 2 outside the AML), with a maximum capacity of 30 daily users, making a total of 432 places, with an occupation of 89% that corresponds to 386 of them occupied (Social Charter, n.d.). The existing Forums were created under Joint Order No. 407/98.

This response proposes to support adults with severe mental illness; with reduced to moderate degree of psychosocial disability; clinically stabilized; with dysfunctions in the relational, occupational and social integration areas. It has a multidisciplinary team, which offers technical supervision and support, at least, 8 hours a day, on weekdays; contact with the community; integration into a stimulating group environment; interventions to promote autonomy, emotional stability and social participation; psychosocial support and rehabilitation for activities of daily living; conviviality and leisure; supervision in medication management; support for family members and other caregivers with a view to family reintegration.

The National Network of Continued Integrated Care for Mental Health providers in analogy Socio-Occupational Units (IUSO), not the ARS LVT does not yet have any socio-occupational unit, having not proceeded to any reconversion of the old Joint Order or created new ones.

# b) Employment Support Measures - IEFP, IP

The support provided by the IEFP (Institute of Employment and Vocational Training) in vocational rehabilitation consists of a set of integrated measures aimed at supporting the qualification and employability of people with disabilities and disabilities, who face difficulty in entering or reentering, maintaining and progressing in the labor market.

Developed in structures accredited by IEFP, IP. As resource centres to support and support employment and specialised intervention services in the field of vocational rehabilitation, information, assessment and guidance for qualification and employment are provided. This modality of action has a maximum duration of 4 months. This type of diligence includes support not only vocational but also financial, both for people with disabilities and for the promoters.

In addition to assistance in the qualification and placement process, these projects also include post-placement monitoring, with the aim of supporting workers and their employers in maintaining employment and career progression.

The Supported Employment model is a program co-financed by IEFP, IP.; PO ISE; Lisbon 2020; Portugal 2020; and European Union – European Social Fund; aimed at people with disabilities and disabilities registered as unemployed in the employment services.

This aims to develop the skills of people and professionals for the exercise of a professional activity that facilitates the transition to the normal work regime.

#### c) Housing First Apartment (HF)

The *Housing First* model is based on the assumption that with the right support, homeless people can choose, obtain and maintain a home, and that having a permanent home in good condition is crucial for the construction of their life project. It begins to be applied in Portugal in 2017, with the Resolution of Ministers No. 107/2017, of July 25, within the scope of the National Strategy for the Integration of Homeless People (ENIPSSA), which establishes the intervention and monitoring models for the period 2017-2023.

AML has about 350 *Housing First* homes for people experiencing homelessness, mental illness and/or substance abuse.

This service offers: permanent individual housing; conception of a life project, with a view to insertion and autonomy; promotion of autonomy through the mobilization of resources; education, vocational training and vocational integration solutions; access to social protection measures; access to health care; social and community insertion actions; and integration (or not) into treatment/rehabilitation programs.

Weekly or fortnightly visits are made lasting from 1h to 1h30 and monitoring services and activities, according to the needs of the person.

# d) Independent Living Support Center (CAVI)

The Independent Living Support Centers are regulated, through: (1) Decree-Law No. 129/2017, of October 9, which creates the Independent Living Support Model (MAVI), which allows people with disabilities to be individually assisted in carrying out activities that they cannot do alone, and where the rules of this personal assistance activity are established, materialized in the creation of the Independent Living Support Centers (CAVI); (2) Decree-Law No. 27/2019, of 14 February, which amends the MAVI program, which clarifies that personal assistance cannot be accumulated with any type of residential support, clarifying the rules that prevent the accumulation of social support.

At ARS LVT there is 1 independent living support centre, with a capacity of up to 50 people at a time. These centers are intended for people over 16 years of age, with a certified disability degree equal to or greater than 60%, or with intellectual disability, mental illness and/or autism spectrum disorder (ASD), regardless of the degree of disability, provided that they are clinically stabilized.

Each CAVI is made up of a multidisciplinary team, formed by professionals from the areas of health, psychology, social action and rehabilitation, depending on the needs of the user. In this system, each beneficiary is assigned a personal assistant, who provides support in carrying out the activities chosen by the first.

# 5. Legal framework

# 5.1. Basic Legislation

Law No. 2118 of April 3<sup>rd</sup> 1963 - establishes the general principles of mental health policy and the guiding principles for the decentralisation of services through the establishment of mental health centres and the link to primary health care. - **REPEALED** 

Law No. 36/98, of July 24<sup>th</sup> 1998 - establishes the general principles of mental health policy and regulates the compulsory internment of people with mental anomalies, namely people with mental illness. – **REPEALED** 

#### 5.2. Current Legislation:

Joint Order No. 407/98, of June 18<sup>th</sup> 1998 - Feasibility of psychosocial rehabilitation programs in Portugal, contributing to important advances with regard to the integration of people with mental illness in the community. - RULING ON A TRANSITIONAL BASIS

Decree-Law No. 101/2006, of June 6<sup>th</sup> - Creates the National Netword of Continued Integrated Care.

Resolution of the Assembly of the Republic No. 56/2009 - Approves the Convention on the Rights of Persons with Disabilities, adopted in New York on 30 March 2007.

Decree-Law No. 8/2010, of January 28<sup>th</sup> - Extension of the National Netword of Continued Integrated Care (RNCCI) to the area of mental health.

Decree-Law No. 136/2015, of July 28<sup>th</sup> - Makes the first change to Decree-Law No. 101/2006, of June 6<sup>th</sup>, which creates the National Network for Continued Integrated Care, and the second amendment to the Decree-Law No. 8/2010, of January 28<sup>th</sup>, which creates a set of integrated long-term care units and teams for mental health.

Legislative Order No. 14-A/2015, of July 29<sup>th</sup> - Normative Order defines the conditions under which the social security contribution is attributed to users for the provision of social support care, within the scope of integrated long-term mental health care.

Resolution of the Council of Ministers No. 107/2017, of July 25<sup>th</sup> - Approves the National Strategy for the Integration of Homeless People: Prevention, Intervention and Monitoring, 2017-2023

Decree-Law No. 129/2017, of October 9<sup>th</sup> - Establishes the Independent Living Support Model program

Decree-Law No. 27/2019, of February 14<sup>th</sup> - Amends the Independent Living Support Model program

*Order No.* 2753/2020 - Creation of a mental health pilot project by regional health administration, including each pilot project a community mental health team for the adult population (ECSM-PA) and a community mental health team for children and adolescents (ECSM-IA).

Decree-Law No. 113/2021, of December 14<sup>th</sup> - Establishes the general principles and rules of the organization and functioning of mental health services

Ordinance No. 311/2021, of December  $20^{th}$  - Establishes the national, regional and local coordination of units and teams of integrated long-term care of mental health

Order 8455/2022 - Creates, in 2022, five community mental health teams for the adult population (ECSM-PA) and five community mental health teams for children and adolescents (ECSM-IA), as provided for in the PRR, and determines that the member of the Government responsible for the health area may authorize recruitment, through the conclusion of open-ended employment contracts, of up to 60 professionals for the aforementioned ECSM-PA and ECSM-IA.

Law No. 35/2023 of July 21<sup>st</sup> – Approves the Mental Health Law, amends related legislation, the Criminal Code, the Code of Execution of Penalties and Custodial Measures and the Civil Code and repeals Law No. 36/98 of July 24<sup>th</sup>.

#### 6. Conclusion

In Portugal. Although, since the 60's, there have been successive legislative changes that reflected international recommendations, with regard to deinstitutionalization and transition to the community, the existing changes have not altered the hospital prevalence in psychiatry. The mental health system in general and psychiatry in particular has belatedly followed the evolution of European psychiatry, at the level of concepts, at the organizational level, and at the level of methods (Alves & Silva, 2004).

Deinstitutionalization and the development of care in the community have been primary objectives in the policies of most European countries, but in Portugal, this process only took place after 1998. The number of beds in psychiatric hospitals has been decreasing from a maximum of 30.6/100.000 to the current rate of 5.5/100.000 inhabitants. Centralization of resources, lack of professional training, insufficient funding and low political priority remained the main barriers to the transition process from hospital-based care to care in the community (DGS, Saúde Mental em Números, 2015).

The movements of deinstitutionalization and the exit of hospitals led civil society and, in particular, private institutions of social solidarity, to the creation and organization of social support responses (in accordance with the legal provisions ruling), which would respond to the housing,

occupational and integration needs in the community of people with mental illness, but these continue today to respond in an incipient way to the identified needs.

Deinstitutionalization, although slow and incomplete, was carried out; there are, however, psychiatric hospitals still in operation, as is the case in the Lisbon Metropolitan Area of the Lisbon Psychiatric Hospital Centre.

Portugal is currently one of the European Union countries with the highest prevalence of psychiatric disorders, access to care continues to be marked by great difficulties and constraints, and funding dedicated to mental health remains very low, although there has been a reversal of the trend in recent years.

The planning of mental health policy is currently based on 3 fundamental instruments: the National Health Plan (PNS), the National Mental Health Plan (PNSM) and the Regional Mental Health Plans (PRSM).

Recent legislative changes aim to change the model of government, reorganize mental health services and give a greater degree of autonomy and decision-making capacity to the structures responsible. On the other hand, the Recovery and Resilience Plan (PRR) aims to complete mental health reform by 2026, with measures, among others, such as the creation of new community mental health teams, and new residential responses in the community to the process of deinstitutionalization of psychiatric hospitals.

The Basic Health Law (Law No. 95/2019, of September 4<sup>th</sup>), Base 13, recommends that mental health care should be people-centred, recognising their individuality, specific needs and level of autonomy, and that they should be provided through an interdisciplinary and integrated approach, primarily at the community level.

Parallel to the new mental health law, it enshrines the rights and duties of people in need of mental health care and regulates the restrictions of these rights and the guarantees of the protection of freedom and autonomy.

It is expected with this new legislative change and investment under the Recovery and Resilience Program the completion of the mental health reform and the deinstitutionalization process, creating the necessary conditions for a more independent life of people with mental illness, with adequate support, and following international guidelines.

# 7. Summary

Residential Typology	Ability	Professional technical support (in daily hours)
Protected Life Unit (UPRO)	11 units 64 seats	Supervision at night and on non-working days.
Autonomous Living Unit (UVAU)	3 units 17 seats	Part-time supervision.
Maximum Support Residence (RAMa)	1 residence 24 seats	Supervision 24 hours a day, every day of the week.
Moderate Support Residence (RAMo)	1 residence 10 seats	Supervision 24 hours a day, every day of the week.
Autonomy Training Residency (RTA)	3 residences 31 seats	Supervision 24 hours a day, every day of the week.
Autonomous Residence of Mental Health (RA)	2 residences 13 seats	Partial supervision.

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# I.C - SERVICES PROVIDED IN THE COMMUNITY OF ROME

#### Contents

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#### 1. INTRODUCTION

#### 1.1 The Health Service in Italy

Health in Italy is protected by the National Health Service (SSN) established by Law No. 833/78, which put an end to a mutual healthcare system, implementing a public, fair and universalistic service, financed through national and regional taxes<sup>1</sup>. The service is organised at the regional level in a system of concurrent legislation with the state, which establishes the fundamental principles of the service and defines the essential levels of care (LEA) that all regions must guarantee. The latters are therefore responsible for the organisation and delivery of health care, which at territorial level is provided by the Local Health Authorities, the point of reference for primary, secondary and specialist care. The services can be provided directly by the Local Health Authority or by an external private entity in outsourcing through an accreditation procedure and the stipulation of contractual agreements that regulate the qualitative and quantitative modalities by which the private entity can perform healthcare activities on behalf of and at the expense of the public health service (Legislative Decree 502/1992 and subsequent amendments and integrations).

As far as mental health is concerned, as can be seen from the institutional website of the Ministry of Health, the main structure of the health service is represented by the Department of Mental Health, which is made up of «the set of structures and services that have the task of taking charge of the demand related to the treatment, care and protection of mental health within the territory defined by the local health authority (ASL)»<sup>2</sup>.

#### The services included are:

- Day care services: the Mental Health Centres (CSM)
- Semi-residential services: the Day Care Centres (CD)
- Residential services: residential facilities (SR) divided into therapeutic-rehabilitative and sociorehabilitative residences
- Hospital services: Psychiatric Diagnostic and Treatment Services (SPDC) and Day Hospitals (DH).

The care offered is completed by university clinics and accredited private nursing homes, as well as home care.

According to the latest data published by the Ministry of Health, 778,737 people in Italy with mental health problems have been assisted by specialist services in 2021 (53.6 % of whom are women)<sup>3</sup>

<sup>1</sup>Citizens who use health services pay a prescription charge, introduced in Italy since 1982, which represents the way, identified by law, by which patients contribute or 'participate' in the cost of health services. This contribution is not due if the citizen has a low income, has particular pathologies (chronic and/or invalidating), or undergoes examinations and screening/vaccination programs promoted at a regional/national level or other controls deemed necessary for the protection of collective health. The services of general practitioners and freely chosen paediatricians are also exempt from prescription charges.

<sup>&</sup>lt;sup>2</sup> This definition of the DSM and the subsequent indications on its services are taken from <a href="https://www.salute.gov.it/portale/saluteMentale/dettaglioContenutiSaluteMentale.jsp?lingua=italiano&id=168&area=salute%20mentale&menu=vuoto">https://www.salute.gov.it/portale/saluteMentale/dettaglioContenutiSaluteMentale.jsp?lingua=italiano&id=168&area=salute%20mentale&menu=vuoto</a> (last consultation 12/5/23) (Our translation)

<sup>&</sup>lt;sup>3</sup> The data are taken from the Italian Ministry of Health, *Mental Health Report. Analysis of data from the Mental Health Information System (SISM). Year 2021*. It should be noted that the overall value of users is deficient in data from the Calabria region.

As far as age groups are concerned, «the highest concentration is in the 45-54 and 55-64 age groups (47.1% in both sexes); females have a higher percentage than males in the >75 age group (5.6% in males and 9.0% in females)»<sup>4</sup>.

#### 1.2 Area of reference: Local Health Authority (ASL) Roma 1

As specified above, each Region is territorially subdivided into Local Health Authorities, which are instrumental bodies through which the Region delivers healthcare. These Authorities are «endowed with broad technical, organisational, accounting and management autonomy, headed by managers (the general directors) appointed by the regions and responsible to them»<sup>5</sup>. The Lazio region consists of 10 ASL's, 6 of which fall within the province of Rome (3 in the city of Rome).

In the Lazio Region's latest programmatic document on mental health<sup>6</sup>, it is specified that the articulation of each Department of Mental Health (DSM), with regard to the care mission aimed at adult psychiatric users, mainly consists of:

- daycare services: Mental Health Centres (CSM), direct access territorial facilities that receive, assess and respond to the mental health needs of citizens over 18 years of age residing in the catchment area, also providing home care services;
- semi-residential services: Day Care Centres (CDs) that promote resocialising activities;
- residential services: residential facilities (SR) divided into therapeutic-rehabilitation residences in-patient and out-patient (SRTR int and SRTR est), socio-rehabilitation residences (SRSR24h, SRSR12h) and flat groups;
- hospital services: the Psychiatric Diagnostic and Treatment Services (SPDC) and Day Hospitals (DH) for the treatment of emergencies and acute crises.

In 2021, 61.177 people with mental health problems were assisted by specialist services in the Lazio Region (Ministry of Health 2022) out of a total population of 5.730.399<sup>7</sup>.

In this paper, we will analyse the specific services included in ASL Roma 1, the territory in which Solaris has always operated. The territory of ASL Roma 1 has 1.041.220 residents, equal to 36.3% of the total resident population of the Municipality of Rome and includes 6 municipalities (I, II, III, XIII, XIV, XV). 8

<sup>&</sup>lt;sup>4</sup> Ibid.

<sup>&</sup>lt;sup>5</sup> Neri, S. (2020), ), 'Più Stato e più Regioni. L'evoluzione della governance del Servizio sanitario nazionale e la pandemia", in *Autonomie locali e servizi sociali*, 43(2), 239-255, p. 244 (Our translation)

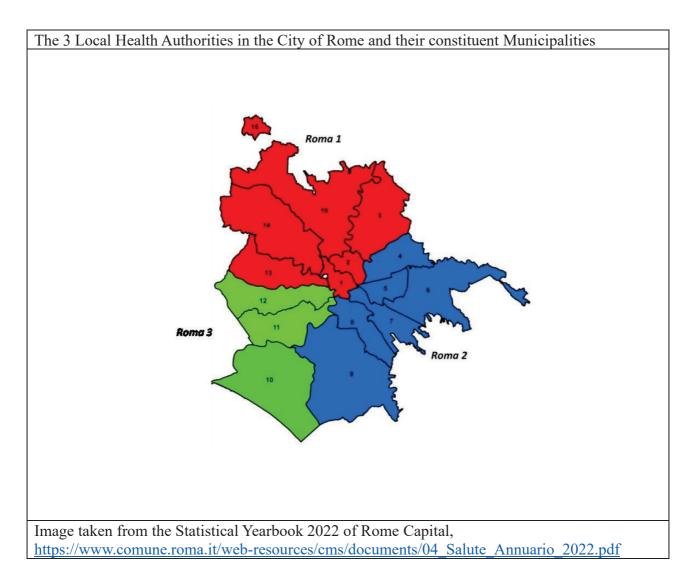
<sup>&</sup>lt;sup>6</sup> Lazio Region 'Regional Mental Health action plan 2022-2024', available on

https://www.regione.lazio.it/sites/default/files/2022-12/Piano-regionale-salute-mentale.pdf (last view16/6/2023)

<sup>&</sup>lt;sup>7</sup> ISTAT (National Institute of Statistics) data as at 1/1/2022. Source <a href="http://dati.istat.it/Index.aspx?QueryId=18544#">http://dati.istat.it/Index.aspx?QueryId=18544#</a>

<sup>&</sup>lt;sup>8</sup> Data taken from

https://www.aslroma1.it/mission#:~:text=Il%20bacino%20di%20utenza%20della,strutture%20di%20erogazione%20de ll'Azienda (last consultation 27/05/2023)



From the ASL Roma 1 institutional site, the structures that make up the **Department of Mental Health (DSM)** and are dedicated to adult users, are articulated and defined as follows<sup>9</sup>:

- The **Mental Health Centre (MHC)**, is the outpatient Centre for the initial intake of users aged 25 years and over;
- The **Psychiatric Diagnostic and Treatment Service (SPDC)** constitutes the specialised hospital Centre;
- The **Departmental Simple Operational Unit (UOSD) Hospital Psychology** provides Psychological support to patients and their families in hospitalisation situations:

<sup>&</sup>lt;sup>9</sup> List taken from <a href="https://www.aslroma1.it/salute-mentale">https://www.aslroma1.it/salute-mentale</a> excluding the TSMREE (Mental Health Protection and Rehabilitation of the Evolutionary Age) dedicated to the 0-18 age group and the PIPSM (Prevention of Early Interventions for Mental Health) dedicated to users aged 14 to 25. Another specific service is that relating to Mental Health and Addictions in in the Criminal Field which assumes the management of the reception, diagnostic assessment and treatment of persons imprisoned in Penitentiary Institutions who present risks or mental disorders and/or substance-related disorders; where there are addiction problems, we also find the SERD (Service for Addiction - Drugs, Alcohol, Smoking and Gambling) and the CRARL (Alcohol Reference Centre of the Lazio Region) which take care of patients with Alcohol Use Disorders (DUA), through the provision of outpatient and day hospital services in conformity with identified methods and paths;

- The **Day Centre (CD)** promotes resocialising activities;
- · Residential Structures
- Planned Domestic Assistance (ADP)

ADP is part of a care pathway based on enabling users to live independently and permanently in their own homes, supporting them to become more and more competent in managing their lives within their own homes.

#### 2. THE SERVICES

The indicated facilities include multiple services that make them operational and which in some cases involve collaboration with local social services.

The first part of this section will describe psychiatric residential services that tend to respond to a care logic close to the «linear continuum housing concept» 10,

That is the development of a gradual continuum of residential treatment programmes through which the patient "progresses" towards better social functioning and thus towards less restrictive settings (Lehman, Newman, 1996)<sup>11</sup>

These are facilities that host users for specific periods of time and have a staff that assists and monitors the daily life of the residents with an intensity that decreases as the level of autonomy recognized to the user increases (Fioritti, Maone, 2015).

A second part will be dedicated to home care, aimed at supporting a different idea of care and residency that focuses on living independently and permanently, avoiding «the dislocation of the patient from his or her natural living environment» and wants to overcome the previous approach, i.e. «the overlapping and confusion between housing needs and care needs» <sup>12</sup>.

A third part will indicate some services that tend to promote independent living, inclusion and socialisation of users.

<sup>&</sup>lt;sup>10</sup> FiorittiA., Maone A., (2015) "La riabilitazione psichiatrica orientata alla recovery. Lavoro e vita indipendent" in *Recovery. Nuovi paradigmi per la salute mentale* (a cura di Maone A. e D'Avanzo B.). . Raffaello Cortina, Milan. (our Translation)

<sup>&</sup>lt;sup>11</sup> Ibid, p.151; the authors here take up the article by Lehman, A., & Newman, S. J. (1996). Housing. In W. R. Breaky (Ed.), Integrated mental health services: Modern community psychiatry (pp. 300-309). New York: Oxford University Press.

<sup>&</sup>lt;sup>12</sup> Ibid, p. 153. In explaining this approach, the authors refer to Ridgway, P., & Zipple, A. M. (1990). The paradigm shift in residential services: From the linear continuum to supported housing approaches. *Psychosocial Rehabilitation Journal*, 13(4), 11–31 (Our translation)

#### 2.1 The residential Services

Starting from the residential services, we can identify in the national strategy, as can be deduced from the document published by the Ministry of Health on 'Psychiatric Residential Facilities' in 2013, the result of an agreement between the State and the Regions<sup>13</sup>, the intention to "differentiate the residential offer by levels of rehabilitation and care intensity in order to improve treatment" (ibid). The same document, also wishing to reduce the regional heterogeneity in the offer of these services, provides national guidelines to «promote, within the offer system of the Departments of Mental Health, a residency functional to individualised paths and structured both by the intensity of treatment (from intensive treatment to socio-rehabilitative support) and by programs and types of intervention correlated to the pathology and the complexity of needs». The following types of facilities are therefore indicated:

- Psychiatric residential facility for intensive therapeutic rehabilitation treatment (SRP1).
- Psychiatric residential facility for extensive therapeutic rehabilitation treatment (SRP2).

The above-mentioned facilities (SRP1 and SRP2) can be articulated on different levels of care intensity, which configure different sub-types.

• Psychiatric residential facility for social-rehabilitative interventions, with different levels of care intensity, divided into three sub-types, with socio-medical staff present 24 hours, 12 hours, by time slots (SRP3).

In line with these indications, in the Lazio Region, the current configuration of residential services, following a decreasing level of intensity of healthcare assistance, is as follows: Territorial Intensive Psychiatric Treatment Facilities, Intensive Residential Therapeutic-Rehabilitation Facilities (as SRP 1); Extensive Residential Therapeutic-Rehabilitation Facilities (as SRP 2); Residential Socio-Rehabilitation Facilities (24H and 12h) and Apartment Groups (SRP 3). These services are paid for by the health service.

Beyond the specific typology, all psychiatric residential facilities must guarantee (ex DCA 3 February 2011 No. 8; ex DCA 468/2017), in addition to family involvement and liaison with the various DSM facilities, also:

- an environment as similar as possible, in terms of times and rhythms of daily life, to a family life context and an emotional climate favourable to community coexistence;
- continuity of social relationships and social life, unless there are justified clinical indications to the contrary;
- socialisation inside and outside the facility, also with the possible contribution of participation and voluntary organisations.

Let us look specifically at the main characteristics of each of them.

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<sup>&</sup>lt;sup>13</sup> Unified Conference Agreement of 17 October 2013

#### a. Territorial Intensive Psychiatric Treatment Facilities

We report from the reference standards (ex DCA 3 February 2011 No. 8; ex DCA 468/2017) the main indications on this service:

- The Facilities for Territorial Intensive Psychiatric Treatment (STPIT) perform diagnostic and therapeutic functions for the treatment of persons with psychiatric disorders whose importance requires a high intensity of care. Access is voluntary and subject to authorisation by the DSM. These facilities must guarantee the necessary continuity of care for users coming from the SPDC and for those coming from the territory, through continuous collaboration and full connection with the facilities of the DSM of origin, i.e. of territorial relevance for taking charge.

Organisational requirements include specific professional figures and their number is established in proportion to the number of beds in the facility:

- Psychiatrists (responsible): 1 regardless of the number of beds;
- Psychiatrists (additional): 3 per 30 beds (to guarantee continuity of presence every day), except at night;
- On-call service: 84 hours (equivalent to 2 full-time units) to guarantee a 12-hour on-call night service:
- Psychologists: 2 for every 30 beds;
- Coordinating nurse: 1 regardless of the number of beds;
- Nurses: 12 per 30 beds (to guarantee 24-hour coverage and shifts of 2 + replacements);
- Therapists / Professional Educators: 2 per 30 beds / Psychology Technicians;
- Health Care Assistant: 3 for 3 per 30 beds (with the possibility of 24-hour coverage);
- Social workers: 0.5 per 30 beds.

The standard stipulates that in facilities the rooms must accommodate a maximum of 4 beds and that in new buildings the patient rooms must accommodate a maximum of 2 beds. In ASL Roma 1 there are 3 STPITs managed by accredited private entities in agreement with the regional health service<sup>14</sup>, for a total of 90 beds. The stay in STPITs should not normally exceed 30 days, after which the user can be directed to other facilities and services of the DSM.

## b. Therapeutic-Rehabilitation Residential Facilities (S.R.T.R.)

We report from the reference standards (ex DCA 3 FEBRUARY 2011 No. 8; ex DCA 468/2017) the main indications on this service

SRTRs are community-based healthcare facilities for the voluntary global treatment - psychotherapeutic, pharmacological, relational and social - of patients, preferably young and in the early stages of psychopathology, with acute, post-acute or sub-acute disorders, who cannot be treated at home, who do not require in-patient treatment and who need temporary and specialised care in an alternative daily-life context.

The S.R.T.R.s (Residential Psychiatric Therapeutic Rehabilitation Facilities), as mediators of the therapeutic relationship, have the purpose of overcoming the acute, post-acute or sub-acute phase

<sup>&</sup>lt;sup>14</sup> Structures identified in the list of 'Accredited private healthcare facilities' of the Lazio Region updated to 2/12/2022 and viewable at <a href="https://www.regione.lazio.it/amministrazione-trasparente/strutture-sanitarie-private-accreditate">https://www.regione.lazio.it/amministrazione-trasparente/strutture-sanitarie-private-accreditate</a> (last viewing 12/06/23)

and favour the acquisition of satisfactory relational skills and adequate levels of personal autonomy.

They are intended for users with exclusive psychiatric disorders - even when they come from the penal circuit or are subject to judicial measures - except for those residential facilities specifically dedicated to patients presenting a comorbidity of psychiatric disorders and addiction/abuse of psychotropic substances.

The S.R.T.R.s guarantee 24-hour assistance and are divided into:

- S.R.T.R.s for **intensive community treatment**: facilities for patients with acute and postacute disorders requiring intensive relational, pharmacological and psychotherapeutic interventions, **with a maximum stay in the facility of approximately 60 days**.
- S.R.T.R. for extensive community treatment: facilities for patients with sub-acute disorders, requiring relational, psychotherapeutic and pharmacological interventions, with a maximum stay in the facility of approximately 2 years and subsequent reintegration in the habitual living context or in an autonomous living context supported at home, or subsequent gradual transition to facilities with less commitment and/or specific care of a sociorehabilitative or socio-welfare nature.

According to the regulations, the staff identified for each type, calculated on a module of 20 beds<sup>15</sup>, must be composed as follows:

- SRTR int
  - Psychiatrists (responsible): 1 regardless of the number of beds
  - Psychiatrists / Psychologists: 3 per 20 beds (of which at least 2 psychiatrists)
  - Nurses: 5 per 20 beds (to guarantee 24-hour coverage and night shifts)
  - Therapists / Professional Educators / Psychology Technicians: 2 per 20 beds
  - Health Care Assistants: 5 per 20 beds (to guarantee also night shifts)
  - Social workers: 0.3 per 20 beds (12h with at least 2 presences per week)
- SRTR ext
  - Psychiatrists (responsible): 1 regardless of the number of beds
  - Psychiatrists / Psychologists: 2 per 20 beds
  - Nurses: 2 per 20 beds
  - Therapists/Professional Educators/Psychology Technicians: 5 per 20 beds (to guarantee also night shifts)
  - Health Care Assistants: 6 per 20 beds (to guarantee also night shifts)
  - Social workers: 0.3 per 20 beds (12h with at least 3 presences per week)

In ASL Roma 1 we find 5 SRTRs directly managed by the DSM and 3 in outsourcing 16.

#### c. Socio-Rehabilitation Residential Facilities (S.R.S.R.)

We report from the reference standards (ex DCA 3 FEBRUARY 2011 No. 8; ex DCA 468/2017) the main indications on this service

Community-based socio-sanitary facilities for the voluntary rehabilitative treatment and social reintegration of adult patients with a stabilisation process of the pathology and disabling aspects,

<sup>&</sup>lt;sup>15</sup> For facilities authorised for less than 20 beds, the professional figures will be reduced proportionally

<sup>&</sup>lt;sup>16</sup> There are 2 accredited entities, but one of them offers both SRTRint and SRTRest and was therefore counted as a dual psychiatric residential service.

who cannot be treated at home or in social care facilities, and who require medium to long-term accommodation in a community or family housing context at different levels of care. The S.R.S.R.s, as mediators of 'social restitution', have the purpose of favouring the acquisition of the greatest possible autonomy to allow the exit from psychiatric care and possible social reintegration, through the return to one's own home, to the family, or to an autonomous housing context supported at home, or the insertion in social-sanitary structures, or the transition to structures of the same type but with a lower level of intensity of social-sanitary protection: the flat group<sup>17</sup>. These should preferably be located in a normal urban residential context and/or easily accessible by public transport, so as to facilitate socialisation processes.

#### The S.R.S.R.s are subdivided into:

- S.R.S.R.s with high socio-sanitary assistance intensity (24 hours/24): facilities for patients with a degree of stabilisation of the pathology and disabling aspects that require continuous 24-hour socio-sanitary assistance protection.
- S.R.S.R.s with medium socio-sanitary assistance intensity (12 hours/24) (the authorisations already given for Cohabitation Communities and Accommodation Communities belong to this category): facilities for patients with a degree of stabilisation of the pathology and with levels of daily autonomy such as to require socio-sanitary assistance protection during only 12 hours during the day. The socio-rehabilitative pathway and the stay in these facilities must be oriented towards a further possible decrease in care and towards the acquisition of the autonomy necessary to leave the psychiatric care setting.

According to the regulations, the staff identified for each type, calculated on a module of 20 beds<sup>18</sup>, must be composed as follows:

#### SRSR 24h

- Psychiatrists (responsible): 1 regardless of the number of beds
- Psychiatrists / Psychologists: 1 per 20 beds
- Nurses: 1 per 20 beds (36 hours divided into daytime time slots for 7 days/week)
- Therapists/Professional Educators: 5 per 20 beds (to guarantee also night shifts) / Psychology Technicians
- Health Care Assistants: 5 per 20 beds (to guarantee also night shifts)
- Social workers: 0.3 per 20 beds (12h with at least 3 presences per week)

#### - SRSR 12h

• Psychiatrists (responsible): 1 regardless of the number of beds

- Psychiatrists / Psychologists: 1 per 20 beds
- Nurses: 1 per 20 beds (36h divided into daytime time slots for 7 days/week)
- Therapists/Professional Educators: 3 per 20 beds / Psychology Technicians
- Health Care Assistants: 3 per 20 beds
- Social workers: 0.3 per 20 beds (12 hours with at least 2 presences per week)

In ASL Roma 1, we find 5 SRSR under direct management of the DSM and 5 in outsourcing 19.

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<sup>&</sup>lt;sup>17</sup> See following typology

<sup>&</sup>lt;sup>18</sup> For facilities authorised for less than 20 beds, the professional figures will be reduced proportionally

<sup>&</sup>lt;sup>19</sup> There are four accredited entities, but one of them offers both SRSR 24h and SRSR 12h and was therefore counted as a dual psychiatric residential service.

#### d. Flat groups

We report from the reference standards (DCA 468/2017) the main indications on this service

Flat groups are public facilities, with a variable degree of protection and under the direct management of the mental health department, for users with a degree of stabilisation of the pathology and sufficient levels of autonomy to require social and rehabilitative support only for part of the day. The flat group welcomes adults who may have already completed a therapeutic rehabilitation programme in residential facilities with a higher level of protection, who have reached a sufficient level of autonomy and who are able to perform daily life functions alone or with variable support. They are often able to carry out occupational and work activities.

In the management of daily life, within a rehabilitation framework, the users of the Flat Group take charge of the basic services of the home (food shopping, meal preparation, cleaning). The objective of the flat group is to give the user the best opportunity to leave the circuit of institutions with high care intensity and a high number of beds after the user has achieved good clinical improvement and a satisfactory recovery of basic and advanced skills.

The conclusion of the user's residential rehabilitation pathway in the flat group is defined by the Mental Health Centre (CSM) team in charge of the user, in agreement with the flat group team, based on the level of achievement of the objectives set in the Individual Treatment Plan (PTI).

The structural requirement of the flat group is that of civil housing, taking care that each room does not have more than two beds. The flats can accommodate a maximum of five people. Each housing unit is attributable to a single flat group. The dwellings to be used for this service are made available to the Mental Health Departments, by the Local Health Authorities (ASL) or local entities, by the Public Welfare and Charitable Institutions (IPAB) or by other public administrations. The mental health department is usually the tenant of the property and the direct manager of the user's project.

The flat group (G.A.) must be located in a normal urban residential context equipped with personal services (ease of provision of food and other daily needs, accessibility to outpatient health facilities in the area and presence of neighbourhood agencies organised in associations, etc.) served by public transport, so as to facilitate the processes of socialisation and personal autonomy.

The socio-sanitary assistance to the users of the flat group is ensured by a professional team of which the following professionals can be members, as a rule:

- a) Psychologist
- b) Professional Educators/Psychiatric Rehabilitation Technician/Psychology Technicians
- c) Health Care Assistant
- *d)* Social Worker of the DSM and/or the Municipality (DGR 395/2017 Participating)

The presence of the aforementioned operators in the flat group varies according to the care needs indicated in the user's individual therapeutic plan (variable degree of protection) and in any case the aforementioned figures may be integrated for the individual user if required by the situation. The overall assistance for each flat group is normally quantifiable at a maximum of 10 hours per week for each group, unless the individual needs of the guest are greater.

*The flat group has no staff present during the night, from 8 p.m. to 7 a.m.* 

In the ASL Roma 1 area there are 8 flat groups for adult psychiatric users under the direct management of the Department of Mental Health (DSM).

RESIDENT RESOURCES ASL ROME 1	SOCIAL-HEALTH ATTENTION
Territorial Intensive Psychiatric Treatment Facilities (STPIT) 3 Facilities (90 users)	24h/24
Residential Facility for intensive Psychiatric Therapeutic Rehabilitation (SRTRi) 1 Facility (10 users)	24h/24
Residential Facility for extensive Psychiatric Therapeutic Rehabilitation (SRTRe) 7 Facilities (87 users)	24h/24
Socio-Rehabilitation Residential Facilities* 10 Facilities (70 users)	12 or 24h/24
Flat groups 8 Facilities (52 users)	10h per week
* The data on accommodation capacity is not complete be the ASL Roma 1 reference site	cause for 4 of these facilities this data is not available on

#### 2.3 Home care services

The Asl Roma 1, in the field of mental health, provides Planned home care that «aims to make users increasingly competent in managing their lives in their own homes» To date, there are 145 users receiving assistance in their own homes (data from October 2022), thanks also to the Department of Social and Health Policies of the Municipality of Rome, which, in close connection with the DSMs, contributes to and finances various projects that integrate the autonomy and support paths in their homes developed by the CSMs. The home care service is provided through accredited entities such as Solaris OdV (voluntary organization), which offers this service in the territory of District 2 of ASL Roma 1 (coinciding with the II Municipality of Rome), includes a pool of 30 users, through a team composed of 1 social worker, 1 psychiatric rehabilitation technician, 1 social and health worker and 2 educators. These figures work in continuous dialogue with operators of the ASL and with referents of the II Municipality of Rome. The service supports the user free of charge

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<sup>&</sup>lt;sup>20</sup> https://www.aslroma1.it/salute-mentale

<sup>&</sup>lt;sup>21</sup> The users calculated here also include those receiving home care and living with their families.

<sup>&</sup>lt;sup>22</sup> The contribution from the municipality to support independent living may take the form of economic support to partially cover housing costs (rent, condominium) or to supplement home care.

in personal care, care of the home environment, completion of bureaucratic procedures, promotion of socialising activities and, where possible, in accompanying the user in the implementation of independent living projects, possibly in co-housing with other users.

#### 2.4 Other services aimed at supporting independent living

Focusing on the process of de-institutionalisation initiated with the closure of asylums and oriented towards disengaging the care pathway from the need for custody in ad hoc protected facilities, we have illustrated the possible non-hospital pathways that a psychiatric user can nowadays face in the territory considered, listing them according to a decreasing level of intensity of health care assistance, then describing home care which allows autonomous living, although supported. To promote autonomous living free from psychiatric residency, we can also place other resources that the territory makes available to psychiatric users.

#### a) Day Care Centre

In the sphere of semi-residential services, as set out in the «Lazio Region's 'Regional Plan of Actions for Mental Health 2022-2024», we find the Day Care Centre, which «is a functional structure for the therapeutic project and social integration, both in critical situations and in long-term treatment; it acts as an intermediary between hospitalisation and out-patient care, between a global intervention and delegation to the family or social context».

There are 65 day care centres throughout the Lazio Region, 61 of which are publicly managed and 4 managed by accredited private organisations, with a total of 1721 places<sup>23</sup>. The day centre has therapeutic-rehabilitative functions and its own professional team, which may be supplemented by operators from external social cooperatives and voluntary organisations. In ASL Roma 1, within the public and private accredited day care centres, there are 15 facilities with a total of 273 places<sup>24</sup>. These centres are engaged in the organisation and implementation of expressive, sports and therapeutic rehabilitation activities, vocational training and refresher courses, as well as socio-recreational activities such as summer holidays, trips, cultural visits and others. The legislation states that Day Care Centres must be open at least 6 hours a day and five days a week. The Municipality of Rome contributes and finances various social activities that complement the projects developed by the CSMs for the Day Care Centres.<sup>25</sup>

#### a) Economic benefits

People with mental distress in the care of mental health departments, based on the assessment of an ad hoc ASL Commission, can benefit from economic benefits, which consist of a Care allowance, considered an integral part of the therapeutic-rehabilitation programme aimed at the social reintegration of the patient and the strengthening of de-institutionalisation paths.

<sup>&</sup>lt;sup>23</sup> Data from the Lazio Region's 'Regional Plan of Actions for Mental Health 2022-2024

<sup>&</sup>lt;sup>24</sup>The number of places is taken from the Determination of 1 February 2022, no. G00964 of the Health and Sociosanitary Integration Directorate on the 'Definition of the need for semi-residential places in day centres for territorial psychiatric assistance for adults in the Lazio Region'. The determination also indicates that there are no users on the waiting list, emphasising the adequate accommodation capacity of the existing centres.

<sup>&</sup>lt;sup>25</sup> Former DPCM 12/1/2017 'Definition and updating of the essential levels of care, referred to in Article 1 paragraph 7 of the Legislative Decree No 502 of 30 December 1992

These benefits are provided by the municipalities through funds allocated by the Lazio Region.

The disbursement is temporary and takes place for the time and in the in the measures determined by the individual rehabilitation therapeutic program of the people assisted.

Patients can benefit from the Care allowance even if they are admitted to residences for the execution of security measures and alternative psychiatric facilities located in other regions, as long as they reside in the Lazio Region.

# Economic benefits are distinguished in:

- 1. <u>extraordinary allowance</u>: this is of an urgent nature and is intended to deal with exceptional situations, in particular, to facilitate the start of the therapeutic process. This allowance is granted only once a year and for a maximum period of three months; it may also be paid in a single instalment and may not exceed €. 800.00;
- 2. <u>Temporary emergency allowance</u>: this is granted and disbursed according to the terms and conditions set out in point 1, pending the allocation of the allowance referred to in point 3 and cannot exceed the amount of €250.00;
- 3. <u>ordinary allowance</u>: this is part of the therapeutic programme and is proposed by the treating team, following a socio-healthcare report specifying the therapeutic purposes of the financial support. The ordinary allowance is paid for a period of one year, is renewable and the monthly amount is up to €. 500.00;
- 4. <u>social reintegration allowance</u>: it is part of the therapeutic programme and is aimed at the social reintegration or de-institutionalisation of the assisted person; it is proposed by the care team, in cases where the user does not have economic means and valid family support. The social reintegration allowance can be used to contribute to housing expenses, for social work insertion and resocialising activities. This cheque is paid for a period of one year, and is renewable; the monthly amount of the cheque can be up to €. 800.00.

#### c. The targeted employment centre

The territory does not have a structured and specific public service for work integration for persons with mental distress<sup>26</sup>. There is a general service dedicated to all persons with disabilities, the Disabled Labour Insertion Service - SILD, through which the Lazio Region, with an office in each province, promotes work insertion and integration with support services aimed at «adequately assessing persons with disabilities in their work capacities and placing them in the appropriate place»<sup>27</sup>. This is done to implement the provisions of Law 68/99<sup>28</sup>, which 'provides that employers, both public and private, are obliged to employ differently-abled workers belonging to the categories indicated in the law itself, to the following extent:

- seven per cent of the employees if they employ more than 50 employees;
- two workers, if they employ between 36 and 50 employees;

<sup>&</sup>lt;sup>26</sup> Thanks to the resourcefulness of public bodies and the third sector and the availability of particular funds, there have been initiatives and experimental programmes that have involved psychiatric users in training and/or accompanying job placement paths. Added to this are the possible training courses that day care centres can include among the activities offered within them.

<sup>&</sup>lt;sup>27</sup> https://www.regione.lazio.it/cittadini/lavoro/sild-servizio-inserimento-lavoro-disabilita

<sup>&</sup>lt;sup>28</sup> This rule was partly amended by Legislative Decree No. 151/2015, regarding recruitment methods, the establishment of lists and rankings.

- one worker, if they employ between 15 and 35 employees<sup>29</sup>.

Targeted employment, promoted by national and regional legislation, is an approach

based on the awareness that disability, whether physical or mental, is not in itself synonymous with a reduction in working capacity. Law 68/1999, provides for the integration of a complex system of services, to assess appropriately, through technical and support tools, the user's disability and working capacity to create a customised project, capable of reconciling with the needs of businesses<sup>30</sup>.

Article 13 of Law 68/99 also provides for the recognition of an incentive to companies that employ disabled people. According to the data of the 10th Report in Parliament on the state of implementation of Law 68/99, in Italy, among the employment of workers with disabilities that were recognised with the incentive in 2019, only 25 % concerned forms of psychic and/or intellectual disability<sup>31</sup>.

Legislation on the one hand, and the activation of ad hoc employment services on the other, have not achieved good results in terms of job placement for the disabled in general and for the mentally ill in particular. As pointed out by a study on the subject by ISFOL (now INAPP- National Institute for Public Policy Analysis), especially in the context of economic crisis,

companies consider it 'costly' in organisational terms to integrate disabled people, especially those with psychological problems. The trade-off between administrative sanctions and the 'cost of integration' of the mentally disabled appears unfavourable, so companies prefer not to comply with legal obligations. More generally, this trend can be read in the context of a phenomenon in which people with mental problems are strongly stigmatised<sup>32</sup>

#### d. The After Us

The 'After Us' law, i.e. Law No. 112/2016, came into force on 25 June 2016 and presents an action plan aimed at guaranteeing the welfare, social inclusion and autonomy of persons with severe disabilities and deprived of family support. With the establishment of a specific national fund that is distributed among the Regions, the *Fund for the assistance of persons with severe disabilities deprived of family support*, the law, in addition to outlining important financial instruments for these particularly fragile individuals<sup>33</sup>, indicates specific goals to be achieved:

a) activate and strengthen intervention programmes aimed at favouring deinstitutionalisation paths and support for home-help in residences or flat groups that reproduce the living and relational conditions of the family home and that also take into account the best opportunities offered by new technologies, to prevent the isolation of people with severe disabilities;

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<sup>&</sup>lt;sup>29</sup> Ibidem

<sup>&</sup>lt;sup>30</sup> Venturi, Giulia, et al. Politiche del lavoro e salute mentale: L'integrazione socio-assistenziale come strumento per favorire percorsi di recovery." *GIORNALE ITALIANO DI MEDICINA DEL LAVORO ED ERGONOMIA* 43.1 (2021): 34-39 (our translation)

<sup>&</sup>lt;sup>31</sup> X Report to Parliament on the state of implementation of Law no. 68 of 12 March 1999 "Rules for the right of disabled people to work", available at <a href="https://www.lavoro.gov.it/temi-e-priorita-disabilita-e-non-autosufficienza/focus/x-relazione-al-parlamento">https://www.lavoro.gov.it/temi-e-priorita-disabilita-e-non-autosufficienza/focus/x-relazione-al-parlamento</a>

<sup>&</sup>lt;sup>32</sup> Searchable on <a href="https://oa.inapp.org/jspui/bitstream/20.500.12916/2234/1/Isfol\_FSE197.pdf">https://oa.inapp.org/jspui/bitstream/20.500.12916/2234/1/Isfol\_FSE197.pdf</a> (Our translation)

<sup>&</sup>lt;sup>33</sup> Among the instruments delineated by law we find insurance, establishment of destination restrictions, trusts and special funds, by private entities, in favour of persons with disabilities considered severe

- b) carry out, where necessary and, in any case, on a residual basis, in the best interests of persons with severe disabilities, interventions for temporary permanence in an extra-family housing solution to cope with possible emergencies, in compliance with the wishes of persons with severe disabilities, where possible, their parents or those who protect their interests;
- c) carry out innovative residential interventions for persons with severe disabilities, aimed at creating family-type housing and co-housing solutions, which may include the payment of the costs for purchasing, renting, renovating and installing the systems and equipment necessary for the operation of such housing, also by supporting forms of mutual aid between persons with disabilities;
- d) develop, for the purposes referred to in the letters (a) and (c), awareness-raising, empowerment and skills development programmes for the management of daily life and the achievement of the highest possible level of autonomy for people with severe disabilities.

The regions distribute the funds among the purposes indicated in the law and disburse them to the local authorities. The latter are responsible for receiving requests for support and, with the intervention of local health service operators<sup>34</sup>, for assessing the extent of the need expressed to decide on the path to take.

If we look at the territory falling within ASL Roma 1, to date there are 250 citizens with severe disabilities (physical and/or mental) whose requests for interventions related to Law 112/2016 have been accepted.

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<sup>&</sup>lt;sup>34</sup> The assessment of the applications that the local authorities receive regarding the interventions that can be financed according to Law 112/2016 takes place through the Multidimensional Assessment Unit (UVMD) that in the Lazio Region, as can be seen from a specification on the subject contained in DGR698/2022, "can vary in relation to the need and includes, in addition to the general practitioner, the nurse, the social worker, the district doctor, and is integrated, depending on the specific needs of the user, by other professional figures (medical specialists, rehabilitation therapist, psychologist, other figures) pertinent to the territorial services/operating units. Moreover, as specifically indicated in the Regional Social Plan, in relation to the specific situation, the UVMD may be supplemented by the person directly concerned, by other professional figures belonging both to the ASL services and to the social services of the municipalities and/or to other bodies/institutions and/or organisations in the territory, and, when useful and necessary, also by subjects who take care of the person to be assessed in any capacity (family caregiver, support administrator, family assistant, teacher, the social cooperative providing the home care service, etc.).

#### 3. CONCLUSIONS

The current structure of mental health services in Italy is the result of a gradual change in the approach to mental illness, substituting the idea of care for that of control and custody that for a long time had conditioned and determined the measures aimed at individuals with mental distress. A path that began with Basaglia's revolutionary experience in Trieste during the 1970s and the law 180/1978 that bears Basaglia's name and that, as Pulini points out, saw the closure of psychiatric hospitals completed between the end of the 20th and the beginning of the 21st century, when in Italy «a national public mental health policy was configured, oriented towards territorial care and the recognition of citizenship rights of persons with mental disorders»<sup>35</sup>.

Admission to psychiatric residential facilities, as emphasised by the Ministry of Health, beyond the specific organisational structures that each region implements in its territory, must represent 'a part of the therapeutic and socio-rehabilitative programme for citizens with psychiatric distress' and these facilities 'have the purpose of offering a network of relationships and emancipative opportunities, within specific rehabilitative activities' and must therefore not be understood 'as a housing solution'<sup>36</sup>.

*Living* is a dimension that can only be achieved at home, restoring to this term «its universal function as a prerequisite for ontological security, the development of identity and self-fulfilment, a social determinant of health and well-being» (Fioritti, Maone, 2015)<sup>37</sup>.

National and regional legislation, as seen in the preceding paragraphs, presents multiple territorial services that can realise autonomous life paths for citizens suffering from mental distress, but the economic crisis on the one hand and the pandemic on the other have reduced these possibilities.

One of the main critical points is the lack of staff. According to data from the National Mental Health Report, «compared to the standard for territorial activities, 3,638 operators are missing»<sup>38</sup>.

The shortage of resources is accompanied by a growing demand for mental health care, which the pandemic years has strongly increased, especially among young people. In particular, among the latter, the data of an international study speak for themselves: one in four adolescents presents the clinical symptoms of depression and one in five of anxiety disorder; in both cases, the numbers have increased compared to the pre-pandemic data<sup>39</sup>

It is clear the need to invest more than ever in mental health services in a country which, as Starace, president of the Italian Society of Psychiatric Epidemiology (SIEP), points out, «is recognised as an international leader in community-based MH [mental health]<sup>40</sup>" and which, however, "ranks last in

<sup>&</sup>lt;sup>35</sup>D. Pulino - Le metamorfosi della politica di salute mentale italiana (1978-2013), in "Cartografie sociali : rivista di sociologia e scienze umane : V, 9, 2020, Milano : Mimesis, 2020, p.175 (Our translation)

 $<sup>\</sup>frac{36}{https://www.salute.gov.it/portale/saluteMentale/dettaglioContenutiSaluteMentale.jsp?lingua=italiano\&id=168\&are\\ \underline{a=salute\%20mentale\&menu=vuoto}$ 

<sup>&</sup>lt;sup>37</sup> "la riabilitazione psichiatrica" p.153 (Our translation)

<sup>&</sup>lt;sup>38</sup> Dall'articolo di F. Starace 'Salute mentale: organizzazione, strutture e personale. Cosa prevede il decreto con i fabbisogni approvato dalla Stato-Regioni' del 13/1/2023 su quotidianosanità.it <a href="https://www.quotidianosanita.it/studi-e-analisi/articolo.php?articolo\_id=110206">https://www.quotidianosanita.it/studi-e-analisi/articolo.php?articolo\_id=110206</a> (Our translation) (last viewed 16/6/2023)

<sup>&</sup>lt;sup>39</sup> See the article 'Salute mentale. Un adolescente su 4 ha sintomi di depressione da Covid, raddoppiati i casi in 2 anni' published on quotidianosanità.it il 26/1/2022

and available at https://www.quotidianosanita.it/scienza-e-farmaci/articolo.php?articolo\_id=101769

<sup>&</sup>lt;sup>40</sup> The public financing of Mental Health and the need for extraordinary intervention, by Fabrizio Starace in quotidianosanità.it of 9/5/22. Available on

terms of the share of health expenditure dedicated to MH»<sup>41</sup> with a value of 3.4% recorded by the OECD (Organisation for Economic Cooperation and Development) in a publication of 2021<sup>42</sup>. Above all, this percentage is far from the 5% target set in the objective projects (Objective Project 1994-96 and subsequently that of 1998-2000) with which the architecture of mental health services in Italy was designed in the 1990s.

In addition to greater financial investments, it would be desirable to strengthen greater involvement of users, making them protagonists of their life paths and setting up an integrated system of resources. A tool that goes in this direction is the *Budget di salute* (BdS or, in English, Personal health budget, PHB), i.e. the predisposition of a budget «made up of all the economic, professional, human and relational resources necessary to promote relational, family and social contexts suitable to favour a better social inclusion of the person»<sup>43</sup>.

With this tool, the social and health needs of frail users are not managed according to the range of services available but through a process of co-planning, operators and users try to place themselves on a more or less equal footing, an attempt is made to define the current situation together and, on the basis of individual preferences, goals are set and, in a creative process, will be searched for the economic and human resources needed to achieve them<sup>44</sup>"

Although there are no uniform indications at the national level<sup>45</sup>, many regions have adopted legislative acts concerning the health budget, proposing it especially in the area of mental health. The Lazio Region contemplates this tool in the regional law on the 'Integrated System of Interventions and Social Services' (L. 11/2016), in the regional guidelines on 'During and After Us' (Resolution 554,5 August 2021) and in the latest *Regional Plan of Actions for Mental Health 2022-2024*. Although still on an experimental basis, this tool is gaining ground by showing the possibility of managing resources in a completely new perspective that is closely tailored to the specific needs of each user.

https://www.quotidianosanita.it/studi-e-analisi/articolo.php?articolo\_id=104573#\_ftn12 (last viewed 16/6/2023) d1 lbid.

<sup>&</sup>lt;sup>42</sup> OECD, A New Benchmark for Mental Health Systems: Tackling the Social and Economic Costs of Mental III-Health. 2021 (Our translation)

<sup>&</sup>lt;sup>43</sup> Franco Pesaresi, The Health Budget in the National Guidelines, article available on <a href="https://www.welforum.it/il-budget-di-salute-negli-indirizzi-nazionali/#easy-footnote-bottom-1-45591">https://www.welforum.it/il-budget-di-salute-negli-indirizzi-nazionali/#easy-footnote-bottom-1-45591</a> (Our translation)

<sup>&</sup>lt;sup>44</sup> Fioritti A., 'Preface. Evidence of future welfare', in Santuari A., The Health Budget and taking charge of frail persons, FrancoAngeli, Milano, 2022, p.14

<sup>&</sup>lt;sup>45</sup> Several national regulations explicitly mention the health budget or imply it but there is no specific definition; in the various references it is always linked to strategies aimed at favouring the de-institutionalisation of frail persons

# Appendix: Main national laws on mental health

	I	al laws on mental health
YEAR	LAW	SUBJECT
1948	Italian Constitution	Article 3 All citizens have equal social dignity and are equal before the law, without distinction of sex, race, language, religion, political opinions, personal and social conditions. The Republic must remove those obstacles of an economic and social nature which, by effectively limiting the freedom and equality of
		citizens, impede the full development of the human being and the effective participation of all workers in the political, economic and social organisation of the country
		Article 32 The Republic protects health as a fundamental right of the individual and an interest of the community and guarantees free care for the indigent.  No one may be obliged to undergo a given health treatment except by the provision of law. The law may under no circumstances violate the limits imposed by respect for the human being
		Article 38 Every citizen unable to work and lacking the necessary means to live is entitled to maintenance and social assistance.  Workers have the right to be provided for and insured with adequate means for their living needs in the event of accident, illness, invalidity, old age and involuntary unemployment.  The disabled and handicapped are entitled to education and vocational training.  The tasks provided for in this article are provided by bodies and institutions set up or supplemented by the State.  Private assistance is free.
1978	Law No. 180 from 13 May 1978 "Voluntary and compulsory health checks and treatments"	Some crucial points of the law, the so-called Basaglia Law, named after the psychiatrist who was its main promoter, are:  - Closure of psychiatric hospitals (asylums) throughout the country and definition of alternative facilities - Health treatment in psychiatry is usually voluntary and primarily related to the person's right to care and health - Territorial psychiatric services as the crux of psychiatric care

		Establishment of Psychiatric Diagnostic and Treatment
		Services (SPDC-PDTs) within general hospitals for the
		treatment of acute cases
1978	Law No. 833 from 23	Main innovations of the regulation: introduction of a
	December 1978,	public system of a universalistic nature that guarantees
	"Establishment of the	health care for all citizens by supporting equity of
	National Health Service"	treatment; centrality of the person (integration of
		prevention, treatment and rehabilitation); need for an
		integrated approach between health policies, social
		policies and environmental policies for the well-being
		of the individual and the community. The law
		transposes the psychiatric reform introduced by Law
		180/1878. The law indicates among the competences of
		the National Health Service, «the protection of mental
		health, giving priority to the preventive aspect and
		incorporating the psychiatric services into the general
		health services so as to eliminate all forms of
		discrimination and segregation, even in the specificity
		of the therapeutic measures, and to favour the recovery
		and social reintegration of the mentally disturbed». The
		regulation requires regional laws to establish territorial
		services for the prevention, treatment and rehabilitation
		of mental illness within departmental structures, both
		<u> </u>
		in-patient and out-patient

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		Law 68/99 establishes minimum quotas of disabled persons that companies must compulsorily employ internally, calculated on the basis of the number of total employees of the same company.  This rule was partly amended by Legislative Decree No. 151/2015, regarding recruitment methods, the establishment of lists and rankings.
1999	Presidential Decree of 1 November 1999, Approval of Objective Project "Mental Health Protection 1998- 2000".	Following in the footsteps of the previous Objective Project, the decree indicates as fundamental actions for the protection of mental health (*):  - the implementation by the services of an operational practice aimed at actively and directly intervening in the territory (home, school, workplace, etc.)  - the formulation of personalised therapeutic-rehabilitation plans  - the integration into these plans of the contribution of other health services, general practitioners, social welfare services and other resources in the area, particularly regarding work, housing and so-called relational goods (production of emotional and social relationships)  - the application of therapeutic strategies judged to be most effective, in the light of the criteria of Evidence Based Medicine  - family involvement in the formulation and implementation of the treatment plan  - the activation of specific rehabilitation programmes for patients who do not turn up for appointments or who drop out of the service, in order to reduce also the incidence of suicide among users  - support for the establishment and operation of mutual help groups of family members and patients and of social cooperatives, especially those with the purpose of job placement carrying out information initiatives, aimed at the general population, on serious mental disorders, to reduce prejudice and spread attitudes of greater solidarity
2000	Law no. 328 of 8 November 2000, "Framework law for the implementation of the integrated system of interventions and social services".	The law recognises the need for coordination and integration between all social policy actors, and therefore the cooperation between social and health services is indispensable in promoting the well-being of citizens. It defines the principles and competence of local authorities in the field of social services. It requires the regions to periodically plan interventions

		through the involvement of the third sector. It recognises a leading role for municipalities in organising services according to general guidelines provided by the regions.
2001	Constitutional Law No 3 of 18 October 2001, «Amendments to Title V of Part Two of the Constitution».	Devolution: attribution of exclusive legislative competence to the regions in many areas that previously constituted matters of concurrent competence between the state and the regions; among these, social services become the exclusive competence of the regions while the state is called upon to set the essential levels of services concerning civil and social rights.
2008	Publication "National Guidelines for Mental Health", by the Ministry of Health	Among the indications, it is emphasised that psychiatric residential facilities are to be understood as «intermediate structures whose function is to support and accompany persons who express discomfort and psychological suffering in the re-appropriation of their dignity and autonomy and that they cannot be conceived as a permanent housing solution».
2010	Decree of the Ministry of Health of 15 October 2010, "Establishment of the Mental Health Information system".	The establishment of a Mental Health Information System, as can be seen on the Ministry of Health website, makes it possible to set up an integrated database of users and services, which can be shared between health authorities, autonomous regions or provinces and central administrations. These data represent a fundamental pool of information in the monitoring, evaluation and planning of mental health interventions. From these data, the "Mental Health Report" is extrapolated every year, which represents a nationwide analysis of the data collected throughout the territory.
2013	Agreement Unified State-Regions Conference No. 4 of 24 January 2013, Approval of the "National Action Plan for Mental Health (PANSM)".	It defines the health objectives for the population, the actions and actors required to achieve them, and the criteria and indicators for verification and evaluation. One of the objectives of the PANSM is to address the issue of psychiatric residential care, proposing specific actions aimed at differentiating the supply of residential care by levels of rehabilitation and care intensity to improve treatment and reduce inhomogeneity. Provides guidelines in the identification of treatment pathways for certain severe psychopathological groupings such as schizophrenic disorders, mood disorders and severe personality disorders, as well as for neuropsychic disorders of developmental age

2013	Agreement Unified State-Regions Conference no. 116 of 17 October 2013 on the document concerning "Psychiatric Residential Facilities".	Following the PANSM's indications, the State-Regions Conference approved the document "Psychiatric Residential Facilities", which defines guidelines homogeneous throughout the national territory, to, as the document itself states, «promote, within the system of Mental Health Departments, a residential facility that is functional to individualised pathways and structured both by treatment intensity (from intensive treatment to socio-rehabilitation support), and by programmes and types of intervention correlated to the pathology and the complexity of needs».	
2014	Law no. 81 of 30 May 2014, "Conversion into law, with amendments, of Decree-Law no. 52 of 31 March 2014, containing urgent provisions regarding the overcoming of judicial psychiatric hospitals"	The law outlines the path to the elimination of the judicial psychiatric hospitals (OPGs), detention facilities intended for the hospitalisation of persons suffering from mental disorders, considered dangerous to public safety and subject to a form of pre-trial detention. The elimination of the OPGs was followed by the establishment, by the regions, of 'Residences for the Execution of Security Measures (REMS)' with a limited number of beds, under medical management and with perimeter security and external surveillance activities, where necessary. These facilities must in any case represent an extreme ratio for persons suffering from psychiatric pathology who have committed a crime, since, to rehabilitate these users, the whole of the local health and social services, of which the Department of Mental Health is a part, must be involved in taking charge.	
	Law no. 112 of 22 June 2016, "Provisions on assistance in favour of severely disabled persons without family support".	The law establishes the Fund for Assistance to persons with severe disabilities deprived of family support with which to finance actions aimed at ensuring the wellbeing, social inclusion and autonomy of persons with severe disabilities deprived of family support, favouring deinstitutionalisation and housing support paths. The Inter-Ministerial Decree (Ministry of Labour and Social Policies, Ministry of Health, Ministry of Economy and Finance) of 23 November 2016, implementing Law no. 112/2016, set the requirements for the benefits to be paid by the Fund. The Regions, to which the Fund is allocated, define the programming guidelines for the disbursement of the resources needed to implement the interventions on the territory. The concrete implementation of interventions and services is instead the responsibility of the municipalities	
	(*) indications taken from  https://www.salute.gov.it/portale/saluteMentale/dettaglioContenutiSaluteMentale.jsp?lingua=italiano&id=175&area=salute%20mentale&menu=azioni		

Main re	Main regional regulations on mental health		
1979 Region	Regional Law no. 93 of 6 December 1979, "Constitution, Organisation, Management and Operation of Local Health Units and Coordination and Integration of Social Services with Health Services, in Implementation of Law no. 833 of 23 December 1978, Establishing the National Health Service and Presidential Decree no. 616 of 24 July 1977".	The law configures, along the lines indicated by national legislation, the structure of health services and facilities on the territory, contemplating the establishment of dedicated mental health departments (DSM).	
1983 Region	Regional Law no. 49 of 14 July 1983, "Organisation of the Departmental Mental Health Service".	It indicates the activities of the Mental Health Departments (DSM): outpatient and home-based activities; 24-hour emergency response; diagnosis and treatment services; residential services; prevention on the territory and operator training. In Article 8, the service functions of the Department of Mental Health include the provision of economic benefits to assisted persons with mental suffering, to hinder marginalisation processes and promote their social reintegration.	
1997	Regional Council Resolution no. 159 of 28 January 1997, "Approval of guidelines: Closure of psychiatric hospitals and approval of implementation guidelines for the objective project for the protection of Mental Health".	It outlines a process aimed at the definitive overcoming of psychiatric hospitals and institutes, to be carried out also by expanding the network of services under the Mental Health Department, whose functions are regulated here.	
2000 Region	Regional Regulation no. 1 of 3 February 2000, "Regulation for the disbursement to persons with mental suffering of the economic benefits referred to in Article 8, first paragraph, number 3) letter e), of Regional Law No 49 of 14 July 1983".	The regulation disciplines the provision of economic benefits to persons with mental suffering, provided for by LR 49/1983 (Regional Law)	
2000 Region	Resolution of the Regional Council no. 236 of 8 February 2000, approval of the "Regional objective project for the promotion and protection of mental health 2000 - 2002 for adults	In the light of the regulations and guidelines issued at the central level with the National Objective Projects "Mental Health Protection 1994-96 and 1998-2000" the structural, functional and managerial characteristics of the Mental Health Department are redefined	
2006 Region	Regional Law no. 6 of 3 July 2006, "Establishment of the	Establishment of a council to promote, in collaboration with the competent Department of	

	Regional Council for Mental	Health, actions aimed at improving assistance for
	Health".	people with mental suffering
2011 Region	Decree of the Commissioner ad Acta no. 8 of 3 February 2011, "Amendment of Attachment 1 to the Decree of the Commissioner ad Acta U0090/2010 for a) rehabilitation activities (code 56), b) long-term care activities (code 60); c) activities provided in Nursing Homes (RSAs) for performance levels: R1, R2, R2D and R3 - Approval of the Integrated and Coordinated Text called "Minimum authorisation requirements for the exercise of health and social health activities".	Among the various points, the regulation, in the section relating to services for persons suffering from mental disorders, indicates the requirements and types of psychiatric residential facilities, differentiating the offer by levels of rehabilitation and care intensity (this structure will be updated by the Decree of the Commissioner ad Acta 7 November 2017, no. 468) and also specifies that home care represents a way of implementation of the therapeutic project prepared by the Mental Health Centre of territorial competence
2016 Region	Regional Law no. 11 of 10 August 2016, "Integrated System of Interventions and Social Services of the Lazio Region".	Article 26 paragraph 4 indicates that integrated home care is a form of care aimed at meeting the needs of the elderly, disabled, those with mental discomfort, suffering from chronic degenerative diseases, and non-self-sufficient persons in need of continuous care that require social interventions with a health relevance and health interventions with a social relevance
2017 Region	Regional Council Resolution no. 454 of 26/07/2017 - "Regional operational guidelines for the purposes of Law no. 112 of 22 June 2016"	The guidelines provide operational indications to support the development and territorial implementation of the "After Us" system of interventions and services.  These guidelines were updated with DGR no. 554 of 05/08/2021 "Modification and integration of regional guidelines for the purposes of Law no. 112 of 22 June 2016". The Region establishes the amounts to be allocated to the various interventions and distributes the quotas to the local authorities.
2017	Resolution of the Regional Council no. 501 of 3 August 2017, "Act of guidance and coordination on the employment of people with disabilities".	This act represents the current regulatory framework by which the Region defines the procedures for the targeted employment of persons with disabilities with regard to the provisions of National Law 68/1999
2017 Region	Decree of the Commissioner ad Acta no 468 of 7 November 2017, "Reform of Psychiatric Residentially: modification and integration of paragraph 4.3 of DCA 8/2011:Flat group.	This regulation defines the current structure of residential services aimed at psychiatric patients that takes up what was indicated in DCA 8/2011 and introduces the residential typology "Flat Group", replacing that of the Residential Socio-Rehabilitation Structures (S.R.S.R.) with time slots. Psychiatric residential facilities in the Lazio Region are therefore subdivided as follows:

	Abrogation of low-intensity SRSR (with time slots)"	<ul> <li>Territorial Intensive Psychiatric Treatment Facilities</li> <li>Therapeutic-Rehabilitation Residential Facilities</li> <li>(S.R.T.R.)</li> <li>Socio-Rehabilitation Residential Facilities</li> <li>(S.R.S.R.)</li> <li>Flat Groups</li> </ul>
2019	Regional Council Resolution	This planning document indicates, among the
Region	No. 1 of 24 January 2019,	objectives to be achieved in the field of mental health,
	approval of the Regional Social Plan "Taking Care, a Common	the realisation of projects for autonomy, flat groups,
	Good" (three-year plan)	housing support projects, projects aimed at inclusion and socio-occupational integration
2022	Regional Law no. 10 of 17 June 2022, "Promotion of policies in favour of the rights of persons with disabilities".	The Region, in emphasising the need to promote the active participation of persons with disabilities and social organisations in the processes of coprogramming and co-planning of interventions, recognises the use of the health budget as the "set of human, professional, technological, instrumental and economic resources, both public and private, necessary to implement the personalised life project".
2022 Region	Regional Council Resolution No. 762 of 29/09/2022, Adoption of the Regional Plan of Actions for Mental Health 2022-2024 "Health and Inclusion".	Among the indicated objectives, the Plan intends to promote a specific strategic action on Mental Health Housing Support with the definition of regional guidelines for projects aimed at this purpose. It also proposes: the definition of a regional Health Budget model for interventions in favour of persons with mental health problems; the implementation of individualised therapeutic rehabilitation projects based on Health Budgets, with the use of co-planning procedures, participatory planning and networking on the territory, involving Third Sector entities, associations and the voluntary sector.

# CHAPTER II- ACTIVITIES OF THE FAMILY ORGANIZATIONS IN MADRID, LISBOA AND ROME

The activities that the three partners have been carrying out in the territories for over twenty years are very diversified, in some cases they represent services open to the territory while in other cases they are aimed exclusively at their members.

The activities arise from explicit requests from the social base of their organizations or from analyzes of needs identified during the association's life and starting from territorial requests. The services involve more or less users, and the activities of a small association, such as Solaris, involve fewer people, may have more limited objectives and be more limited in time than a large association, such as Amafe, but Solaris' activities are equally diverse and numerous.

The same goes for GIRA, and all activities are clearly oriented towards supporting specific target groups or addressing issues concerning the territory or people in general.

The typology that emerges from the examination of the activities is the following:

- a) Family groups
- b) People with diagnosis
- c) Caregivers
- d) Territory
- e) Independent housing

## a) Areas of intervention dedicated to the family (the family as key subject to recovery and social inclusion)

Mental illness necessarily involves all family members and the activities dedicated to the family unit are numerous and fall into these types of intervention:

- a1. Welcome and information for family members (Amafe, Gira, Solaris)
- a.2 Information and consultancy service (Amafe)
- a.3 Multi-family groups (Amafe, Solaris)
- a.3 Mutual help groups GAM (Amafe)
- a.4 Family home care team (Amafe)
- a.5 Psychoeducational interventions training course (Amafe)
- a.6 Orientation and training (Amafe, Gira, Solaris)
- a.7 Involvement in the corporate bodies of the association, together with users (Amafe, Gira, Solaris)

## b) Areas of intervention dedicated to people with diagnosis

People who have mental problems are the focus of the family associations' activities and even the activities with different main recipients are carried out taking into account the needs of the most fragile person. Services aimed at developing skills and their participation in activities organized by the association and the territory are dedicated to them.

#### - Enhancement of skills

- b.1 Development of emotional skills (Amafe)
- b.2 Strengthening work skills (Gira)
- b.3 Development of social skills (Amafe, Gira, Solaris)
- b.4 Development of creativity through the processing and distribution of original works (Amafe, Gira. Solaris)
- b.5 Training for autonomy (Amafe)

#### - Participation in activities

- b.6 Participation in the corporate bodies of the association (Amafe, Gira, Solaris)
- b.7 Collaboration and participation in events, meetings (Amafe, Gira, Solaris)
- b.8 Involvement in the planning of activities (Amafe, Gira, Solaris)

## c) Areas of intervention dedicated to caregivers (caregivers valued and supported)

The role of caregivers is fundamental in the support and paths towards independence of the person with mental problems.

- c.1 Psychological support (Amafe, Gira, Solaris),
- c.2 Participation in activities and social life (Amafe, Gira, Solaris)
- c.3 Involvement in work paths Employment forums (Gira)
- c.4 Involvement in people's independent life paths (Amafe, Gira, Solaris)
- c.5 Participation in the corporate bodies of the association, together with the users (Amafe, Gira, Solaris)

## d)Areas of intervention in the territory

Some activities are not dedicated to individuals or families, but to the territory, another important element for recovery and social inclusion. The principal activities realize the Networking:

- d.1 With the territory (paper and digital publications, meetings, events, shows) (Amafe, Gira, Solaris)
- d.2 With public bodies (members of commissions and city meetings, organization of projects) (Amafe, Gira, Solaris)
- d.3 With the private social partners (members of national and regional associations of family members, meetings, co-planning of interventions) (Amafe, Gira, Solaris)

## e)Areas of intervention for independent living

- e.1 Identification of independent housing solutions (Gira, Solaris)
- e.2 Participation in the coordination of local actors, functional to independent living (Gira, Solaris)
- e.3 Independent management of own or rented residences and apartments (Gira)

- e.4 Family training for independent life (Amafe)
- e.5 Services to support independent living (home support, activation of a support network for social inclusion, implementation of socio-cultural activities) (Gira, Solaris)

## II.A – FAMILY ORGANIZATIONS IN THE COMMUNITY OF MADRID

- 1. Introduction
- 2. AMAFE's background and current state
  - 2.1. Active members, families and services
  - 2.2. Intervention with families through the services
    - 2.2.1. Welcome and counseling sessions with AMAFE's Information and Guidance Service
    - 2.2.2. Family School for fathers, mothers, siblings, partners and carers
    - 2.2.3. Mutual Aid Groups for fathers, mothers, brothers and sisters
    - 2.2.4. Multi-family groups
      - 2.2.4.1 The essential principles of the conductor's positioning as a multifamily group therapist are.
    - 2.2.5. Comprehensive care sessions with specialist psychologists
    - 2.2.6. The board of directors
- 3. Family care in the Confederation
  - 3.1. Guides and documents that support family intervention
- 4. Family care in UMASAM
- 5. Family care in the Public Services Network
- 6. Conclusions
- 7. Bibliography

## 1. Introduction

European families show a great diversity of values and traditions depending on the historical and geographical context in which they develop. The entities of the FILMI project are located in Portugal, Italy and Spain, where families show a greater tendency towards community, intra and inter-family links, which allows the extension of the support network of family and relatives in times of difficulty.

In Spain, families are an essential pillar in the recovery of family members with mental health problems. The Confederation of Mental Health in Spain published on its official website a survey by the European Federation of Families of People with Mental Illness, whose data reveal that the usual caregiver of a person with a serious mental health problem in Spain is usually a woman aged approximately 64, who cares for a child for an average of 21 years, 6 years more than in other European countries.

## 2. AMAFE's background and current state

AMAFE is a non-profit organization, registered in the National Council of Associations of the Ministry of the Interior. It was founded in 1989 by relatives of people with mental health problems, specifically for the care of people with schizophrenia. The aim of this association is to offer comprehensive help to both people with mental health problems and their relatives. The social base has grown over the years, allowing the support network to be extended and expanding the professional structure and the areas of action by the technical team.

## 2.1. Active members, families and services

We currently have 714 active members, 584 of whom are family members. From the association we maintain close links with families, offering psycho-educational, social and therapeutic spaces for families. These services are:

- Welcome and counselling sessions with the AMAFE Information and Guidance Service.
- Family School for fathers, mothers, siblings, partners and carers.
- Mutual Aid Groups for fathers, mothers, brothers and sisters.
- Multi-family groups.
- Comprehensive care sessions with specialist psychologists.

In addition, the Association's horizontal relationship with families and its leading role is also reinforced through the following:

- Active participation in the strategic direction of the Association through the Board of Directors.
- Regular meetings and assemblies for the social base.

• Participation of associated families as volunteers in the different services and tasks of the Association.

Throughout this document, we will go deeper into the services offered by the association to families, the organised support provided by the Confederation of Mental Health in Spain and the specialised services of the institutions belonging to the public sphere of social services.

## 2.2. Intervention with families through the services

At AMAFE we value the role of families and we offer many specialized services in the development of the family environment when one of the members of the system has a serious mental health problem.

When families contact AMAFE, they first access the Guidance and Information Service, where they are attended to and guided in their needs. In 2022, this department provided 1265 services, with a satisfaction index of 9'6 out of 10.

This department resolves doubts in the field of work and social integration, family dynamics and socio-community care. While it is in charge of referring interested people to the rest of the association's services, or putting them in contact with the procedures to follow in order to benefit from social services, it also leads, organizes and links the following services, which we will explain in depth:

## 2.2.1. Welcome and counseling sessions with AMAFE's Information and Guidance Service

81% of the people we attend to in the association are family members. Between October 2022 and July 2023, this department has attended 713 family members, which means that the percentage is also maintained in the first contact. In this office, the professionals attend to, listen to and welcome the needs and doubts of the families, providing a space free of judgment, where alternatives are offered with the knowledge of the association itself and the Public Network of Social Services.

## 2.2.2. Family School for fathers, mothers, siblings, partners and carers

Almost all of AMAFE's departments are involved in this training aimed at relatives of people with schizophrenia. From the fields of social work, psychology and occupational

therapy, the aim is to offer psychoeducational tools to learn about psychosis and to know how to intervene, act, detect and accompany people who have gone through this process. At the association, we recognise that families play an almost indispensable role in the recovery and care of people who have experienced psychosis, but we also know that a caregiver needs care and that in order to care for them it is necessary to be able to attend to their needs and not leave their own life project to one side. The sessions that are carried out are as follows:

- Introduction.
- Schizophrenia: causes, symptoms, evolution.
- The concept of rehabilitation.
- Stigma and self-stigma.
- Carer overload.
- Psychosocial and community care network.
- Legal protection measures.
- Third sector and AMAFE.

## 2.2.3. Mutual Aid Groups for fathers, mothers, brothers and sisters

AMAFE organizes three GAMs or Mutual Aid Groups. The GAMs are spaces where different people share life experiences related to a specific problem or difficulty. People meet and share their experiences with the intention of improving their situation, learning collectively and providing mutual support. There are a number of "rules" that facilitate coordination and management in the group. These are:

- Speaking in the first person.
- Expressing one's own experience.
- Respect turns to speak.
- Maintain a space for active listening.
- Welcoming new arrivals.
- Do not pass judgment on the experience of others.

Although the aim is for people to meet in an informal space, where there is no professional guidance or simply moderation, it is true that these basic principles can guide the group towards more specific objectives, allowing them to delve deeper into topics of interest from the singularity of personal experience.

## 2.2.4. Multi-family groups

In 2017, AMAFE received training in multifamily methodology from the Manantial Foundation, a non-profit organization formed in 1995 and linked to the Social Services Network of the Department of Social Affairs.

The methodology of the multi-family groups seeks to bring together families who have lived a similar experience, uniting people with a diagnosis and their relatives in the same safe environment. As in mutual support groups, the requirements for interaction are similar:

- Talk one at a time.
- Do not speak for each other.
- Talking about oneself and from oneself.
- Respect each other's speaking time.
- Do not judge.

In this proposal, the intervention of the facilitators is greater, offering spaces for reflection and therapeutic deepening from the point of view and approach of the professionals who guide the session. In this case, we talk about conduction because a revaluation of the therapeutic agents is carried out, which involves social and family encounters with people with similar experiences and desires for family improvement. The objectives of the conductors with respect to the group are mainly four:

- 1. Achieving group cohesion.
- 2. To strengthen the group's reflective capacity.
- 3. Enhancing emotional support.
- 4. Encourage flexibility in communication.

## 2.2.4.1 The essential principles of the conductor's positioning as a multifamily group therapist are.

- Establish an equal relationship.
- Maintain a non-directive attitude.
- Adopt an exploratory attitude.
- Catalyze the therapeutic process of the participants.

## 2.2.5. Comprehensive care sessions with specialist psychologists

On the official website of the association we explain this service very precisely. It is common for some people, after living through complex experiences such as the appearance of psychosis in their lives, or living with certain symptoms, to experience difficulties in regaining a full and satisfactory life.

Some may be afraid to leave home, especially when it is difficult to start their recovery. At AMAFE, we offer comprehensive support. Through this service, we help to start a new path aimed at creating a healthy, happy and satisfactory life for everyone.

This is a specialized psychosocial and family care service, which is carried out in the home of the person who, having a previous diagnosis of psychosis or schizophrenia, presents problems in leaving their home, irregular attendance at Mental Health appointments, little social contact and/or prolonged isolation.

In these cases, AMAFE provides a set of professional services based on intervention techniques of a preventive, educational, welfare and rehabilitative nature, by means of the following system of action:

- Family Interview: Family assessment.
- Home visit for service acceptance: Mutual introduction and assessment of the suitability of the service.
- Establishment of the Therapeutic Alliance between the psychologist, the user and the family.
- Technical Intervention: Home sessions with the user and/or the family, as well as accompaniment in activities of daily living.
- Search for and accompaniment to community resources to reduce the situation of prolonged isolation.

#### 2.2.6. The board of directors

Finally, we believe that establishing a close, horizontal and participative relationship with families allows them to play an active role in the association and improve their support network by meeting with families who seek the same objectives.

The Board of Directors, conferences for members and voluntary participation in activities of interest, allows the objective of active family participation to be achieved.

## 3. Family care in the Confederation

The Confederation of Mental Health Spain is a non-governmental, non-profit organization that was created in 1983 with the aim of bringing together and convening the rest of the associations linked to the field of mental health to provide coherence in intervention and establish unanimous objectives in programming and participation strategy. It is currently made up of 18 regional federations and single-province associations, which bring together more than 340 associations and more than 60,000 members throughout the country. Within the general objectives established by

the Confederation, which link all the associations that form part of its organization, family care and intervention stand out as a fundamental pillar for the comprehensive approach to the mental health of the affected person.

In addition to following a coherent line in relation to the families it serves, the Confederation proposes projects and programmes for the associated entities, supporting the development of the entities in order to provide greater quality in their intervention and guarantee comprehensive care. Currently, the Confederation proposes seven guides and documents that support family intervention.

## 3.1. Guides and documents that support family intervention

- The family in AVIFES. Guide containing information on the role of families in mental illness.
- Family quality of life scale. A guide for professionals to assess the quality of life in families.
- Guide to intervention and support for families of people with disabilities. Document with work proposals in the intervention of families with people with disabilities.
- Psychosocial risk assessment in families using the Andalusian Public Social Services System. Psychosocial risk profiles in families with minors.
- Practical guide for family intervention. Tool for structuring, orienting and evaluating the intervention process.
- Guide to dealing with psychiatric crises in the family environment. Steps to follow in case of crisis situations.
- The forgotten children. The forgotten children.

## 4. Family care in UMASAM

Currently, the Madrid Federation (UMASAM) of mental health groups 16 associations based in the Community of Madrid. Its objective is to contribute to the improvement of the quality of life of people with mental health problems and their families and the defence of their rights, as well as the consolidation, strengthening and representation of the mental health associative movement in the Community of Madrid. Umasam is governed under a democratic functioning and under the principle of representation through the General Assembly, Board of Directors and President.

The associations that form part of UMASAM are:

- ABM: Bipolar Association of Madrid.
- AFAEM-5: Madrid North Mental Health Association.
- AFAEMO: Association of Relatives and Friends of the Mentally Ill of Moratalaz.
- AFAEP: Association of Relatives and Friends of Psychiatric Patients.
- AFASAME: Association of Relatives and People Affected by Mental Health.
- AFEM: Getafe Mental Health Association.
- ALUSAMEN: Association in the Struggle for Mental Health and Social Change.

- AMAFE: Spanish Association for Psychosis Support.
- AMAI-TLP: Asociación Madrileña de Ayuda e Investigación del Trastorno Límite de la Personalidad.
- APASEV: Association for Help, Health, Hope and Life.
- ASAM: Association for Health and Mutual Aid.
- ASAV: Asociación Salud y Alternativas de Vida.
- ASAVI: Asociación Salud y Vida Sierra Noroeste de Madrid.
- ASME: Madrid East Mental Health Association.
- AUSMEM: Association of Mental Health Users of Móstoles.
- ASOCIACIÓN PSIQUIATRÍA Y VIDA: Psychiatry and Life Association.

## 5. Family care in the Public Services Network

In the Community of Madrid, specialised care is organised through the Regional Ministry of Families, Youth and Social Policies.

The Family Support and Meeting Centres (CAEF) operate throughout the Community of Madrid. These services offer specialised, free and confidential attention to families who ask for help. Their main objective is to help families to improve communication or dialogue, as well as to deal with the conflicts that arise on a day-to-day basis. The municipalities in which they operate are:

- CAEF Alcorcón Móstoles.
- CAEF Majadahonda Las Rozas.
- CAEF Madrid Central.
- CAEF Torrejón de Ardóz.
- CAEF South.

The Madrid City Council also manages seven Family Care Centres (CAF) that expand their scope of action to the 21 most central districts. These centres have interdisciplinary teams of experts in family intervention made up of professionals in the fields of psychology, law, social work, mediation and administrative staff. The areas of intervention are:

- Information for families and professionals.
- Social Orientation.
- Legal advice.
- Psychological care in the face of difficulties in the field of family relationships.
- Care and prevention of violent relationships in the family.
- Family mediation.
- Family training.
- Community participation (collaborating with the social network).

The Community of Madrid offers eight guides for families, under the name "the family counts" with a total of 845 pages dedicated to training families in conflict resolution, improving family relationships, overcoming life crises and coexistence.

How to resolve family conflicts.

The family in difficult times.

Bullying and family-based violence prevention.

How to live with adolescents.

How do our children grow up?

Emotional intelligence.

Eating disorders.

The family dialogues and reaches agreements. Family mediation.

## 6. Conclusions

AMAFE is an association that belongs to the third sector, specifically to the field of mental health. It serves 714 members, 584 of whom are family members. The differentiating factor of the association with respect to other services is that it has a consolidated family support network that shares the knowledge derived from its own experience through the Mutual Help Groups, members' meetings or participation in the Board of Directors. In addition, the rigorous and specialised knowledge of the professionals allows, among many functions, to guide families in new and complex situations, to offer psychoeducation spaces on mental health, to support families to face moments of crisis, to offer strategies to promote autonomy, etc.

AMAFE also belongs to the Mental Health Confederation of Spain, which organises mental health associations at national level, and to the Mental Health Federation of Madrid (UMASAM), which coordinates 16 non-profit organisations focused on improving the personal, family, social and community life of people with mental health problems. Membership of these organisations allows for coordination with other associations in the mental health field and access to a larger network of families experiencing daily challenges.

In the Community of Madrid, there are resources of the Social Services Network focused on family care and conflict resolution. These are the CAEF (Family Support and Encounter Centres) and the CAF (Family Care Centres). Both services are free of charge and do not require referral from any other centre, i.e. families can access them on their own.

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## II.B – FAMILY ORGANIZATIONS IN THE COMMUNITY OF LISBOA

## ACTIONS CARRIED OUT BY FAMILIES IN MENTAL HEALTH

- 1. Introduction
- 2. GIRA and families
  - 2.1. How it came about
  - 2.2.The answers
  - 2.3. The relationship with families
  - 2.4.The intervention
- 3. Family Associations
- 4. Responses for families in the public services network
- 5. Conclusions
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#### 1. Introduction

The family is a form of human grouping based on ties of kinship and affinity, which is in permanent change to adapt to the needs of its members and the changes in the context that surrounds it, and has undergone an accelerated change in its role in society and its form of internal organization, from the mid-twentieth century (Fazenda, 2008). In the case of families that have a member with mental illness this process of adaptation to their needs becomes much more complex and difficult to manage.

According to Fazenda (2008) "in recent decades the role that families play in the care of a family member with chronic mental illness has been recognized as a valuable collaboration in their treatment and rehabilitation, since it has been found that patients evolve better when they have the support of the family". On the other hand, we have witnessed an important and increasingly privileged role of families in public policy discussions, because patients in most cases become unable to fight for their own rights, so families are invited to become allies and actively participate in the therapeutic process of their loved one, as well as in the struggle for better mental health conditions (Moreno & Alencastre, 2003).

But it was not always like that, initially Pinel points out the possible causes for mental illness, which was formerly thought to be an organic lesion of the brain as: heredity or moral causes, in which the treatment consisted of replacing the environment where the patient resided in order to cure him. Thus, the patient would be in the care of a psychiatric institution and the family banned from the patient's follow-up, allegedly for worsening of psychiatric symptoms when the patient had contact with family members. Currently, these visits are a right of family members and users who are hospitalized (Moreno & Alencastre, 2003).

The way mental health technicians began to face families changed, no longer considering the family as a cause of the disorder (pathogenic families), to see the family as a resource and a partner (Fazenda, 2008).

In the 1990's psychosocial rehabilitation in Portugal had important advances, thanks to the initiative of NGOs that began to develop new structures and services, which was due to the emerging movement of various professional groups and also of users and families.

The GIRA – Grupo de Intervenção e Reabilitação Ativa (Active Intervention and Rehabilitation Group), arises in this context, being a private institution of social solidarity non-profit, founded in 1995, by family and friends of people with severe mental illness. It is created following the deinstitutionalization movements in the 1990s, and is one of the first experiences of integration in community residences, of people who were hospitalized for many years in the Miguel Bombarda

Psychiatric Hospital, which was the first medical institution dedicated exclusively to the hospitalization of people with mental illness in Portugal.

Since then, it has supported people with severe mental illness and psychosocial disability, with the mission of promoting the rehabilitation and social inclusion of people with mental illness, investing in their potential and proximity to caregivers and the community.

Over the years it has been expanding its intervention, in accordance with the legal provisions ruling, seeking to respond to the needs of the territory, currently having: 6 residential structures, 2 occupational structures and 3 *housing first* apartments. It has also sought to develop other projects and complementary responses in order to cover other needs of people with mental illness and their families.

GIRA has a multidisciplinary team that bases its intervention on the community model of intervention, where the participation and self-determination of the person with mental illness is evidenced, which is an active element in their rehabilitation process. It has focused its action in the field of psychosocial rehabilitation, creating alternatives that accompany social phenomena and meeting the emerging problems in the area of mental health, as well as in the search for innovative intervention methodologies.

The families constitute themselves as a partner in the intervention with the users, being involved in the whole rehabilitation program of their family member and seeking their involvement in the dynamics of the organization.

## 2. GIRA and families

#### 2.1. How it came about

GIRA began its intervention in 1995 with the creation of residences in the community, intending at the time to respond to the needs of families who had their relatives hospitalized in psychiatric hospitals and who, faced with the possibility of leaving, considered that they were not able to support them.

It arises from a civil society movement and the desire of a group of families and friends of people with mental illness to create alternatives in the community, being the founding partners families. It should be noted, however, that a group of professionals from the Miguel Bombarda Hospital promoted and supported this start-up, giving knowledge of the experiences in other European countries and how they were successful and providing the confidence necessary for the creation of the association.

It is created, with the following objectives:

a) Promote the quality of life of the person with mental illness in their living environments;

- b) Create support groups at the level of integration of the person with mental illness, according to the various existing needs (areas of work, housing, education, family, etc.);
- (c) To support and defend the rights and legitimate interests of the families of persons experiencing mental illness;
- d) To defend and pronounce on health, education and vocational training policies that guarantee the prevention, treatment, monitoring, social and professional integration of people with experience of mental illness;
- (e) To promote positive and non-discriminatory social understanding of families and persons experiencing mental illness;
- f) Develop joint actions with other entities (official or private) in order to contribute to the definition of mental health policy.

#### 2.2. The Resources

Over the years it has been expanding these responses, creating until 1999 - 4 residences for people with severe mental illness (3 protected living units and 1 autonomous living unit), under Joint Order No. 407/98, with cooperation agreements concluded between the Ministries of Health, Labor and Solidarity, residing in them 24 people.

With the deinstitutionalization movements, families found themselves with their relatives at home and without answers in the community; The integration in these structures, without a defined length of stay, allowed these people to become autonomous from the families, which otherwise became very difficult, to have a life beyond the family.

With the process of deinstitutionalization was evident an overload of the relatives, due to the care that began to be done mostly by the family, hence the importance of creating support networks not only for the patients, but also their families, because if the family can not count on a network of services that helps in the difficulties, There is a trend of consecutive hospitalizations of patients with mental illness and families completely destroyed with these difficulties. The need for a relationship between patient, family, community and technical team has emerged more and more (Souza et al., 2011).

These programs enabled a response in the community to acquire and maintain basic skills, with a view to a life with greater autonomy and quality of life; they allowed the extension of the relational network, as opposed to what happened in a hospital context; promoted greater involvement in community activities; and reduced hospitalizations.

As mentioned, following the deinstitutionalization movements, reinforced with the publication of Law No. 36/98, there was a need to create these responses in the community, so it was

sought that residential support programs provide "activities and resources oriented to favor the permanence and active participation in the social life of people with mental health problems, through the provision of care and fulfillment of the basic needs of daily life, such as: a place to live, the monitoring of the disease and the provision of basic care" (Ferraz, 2005, p. 236).

Subsequently, it became urgent to create occupational responses that would respond to people's occupation needs during the day, promoting socialization as well as socio-professional skills, with a view to integration into training or employment. Fórum Sócio-Ocupacional (Socio-occupational day center)

Thus, in 2000, the first Fórum Sócio-Occupacional (Socio-Occupational Day Center) of GIRA, with capacity for 30 people with severe mental illness, was created in Lisbon, with a cooperation agreement with the Social Security (Lisbon District Center), under Joint Order No. 407/98. In 2002 a new Day Center is established in Almada, with capacity for 25 people, initially through the "Project to Fight Poverty" and since 2006 with a cooperation agreement with Social Security (Setúbal District Center).

In the Day Centers it is intended to develop occupational activities that promote the autonomy of oneself, interpersonal relationships and the development of social and professional skills, with a view to their social integration. For many families, it was a significant support, because otherwise they would often have a tendency to disinvest from the process, with manifest losses for the family, themselves and the community.

These 6 responses remain in operation to this day, giving GIRA through these residential and occupational structures direct assistance to about 60 users (some users integrate simultaneously the residential and occupational structure) and indirectly supporting their families, always in the search for improving the quality of life of users and their families

Between 1998 and 2004 GIRA also developed vocational training courses, with the financial support of the IEFP (Institute of Employement and Vocacional Training). GIRA also created another NGO only focused on the professional training of people with mental illness, called INOVAR, also with financial support.

Due to the numerous requests for residential responses for autonomy training of people with mental illness, made by themselves, family members and professionals, and given the lack of opportunities to create typified responses, due to various constraints of the RNCCI (National Network of Continued Integrated Care) - ruling legislation, GIRA has created since 2020 a pilot project with 2 Autonomy Support Residences (RSA), with capacity for 5 and 7 people, thus supporting 12 more people in total, in the municipalities of Lisbon and Almada. The RSA that is installed in Almada has the support of the Almada City Council, in the transfer of an apartment in a lending contract for the

operation of this unit. These residences are intended for people with higher rehabilitative potential with less need for supervision, however they need some daily monitoring (with reduced time) for the organization of domestic issues and life project.

Through a consortium of entities from the municipality of Almada and having the Almada City Council (CMA) as the promoter in the PIIPSSA project (Integrated Intervention Program with People in Homelessness in Almada), through an application to Portugal 2020 for 3 years (09/2020 to 09/2023), GIRA as a partner currently manages 3 individual apartments, for people with mental illness who were homeless and supports in case management. After the end of the program, the CMA assumed its continuity.

## 2.3. The relationship with families

GIRA currently supports 75 people in the different responses it develops in the territory.

Faced with the creation of social responses, GIRA has become increasingly professionalized, since for their development it was necessary to set up multidisciplinary teams. Nevertheless, the families remained present in the organization, through the direct support given to their relatives with illness and indirect support to the families themselves, being involved in the entire recovery process; as well as through its participation in the social bodies of the institution (General Assembly, Fiscal Council and Direction), basic organs to the functioning and management of the organization. It should be noted that the bodies are also composed of users, professionals and other members of the organization.

According to a study conducted at GIRA in 2016 on Psychosocial Rehabilitation and Quality of Life – contributions of psychosocial rehabilitation programs (Santos and Pedrosa, 2017), although the age of the users of the Day Centerss is mainly between 31 and 60 years, in 74% parents still stood out as the main caregiver/significant, although they were older people. In the case of the residences, siblings stood out in 42% of the users, because the fact that they no longer had the support of their parents, in the face of their estrangement or death, led to siblings appearing as the main support; Other relatives followed; and there were 25% without any contact with relatives, which represented a total estrangement from the family, there having been a rupture with it, and it was not possible, most of the time, to re-establish this bond. According to Liberman (1992) "the volatile course of repeated psychiatric disorders robs the patient of family and social supports that could protect him from stress and improve his quality of life" (cited by Guterres, 2005:117).

Although most families are involved and present in the life of their relative, there are situations of estrangement, weak ties, distant relationships, or even lack of support or family contact, being more noticeable in the users of residential structures. Part of the team's work also focuses on re-

establishing or strengthening these very fragile family relationships, fostering the participation of family members in GIRA's events, the invitation to do leisure programs together or even the promotion of social and behavioral skills to manage conflicts that arise frequently.

Between 2012 and 2014 were developed by GIRA - Family Meetings, with a bimonthly periodicity, with the objective of creating a space for sharing and dialogue between family members and with a component of psychoeducation, seeking to find strategies to deal with the relative, identify signs and symptoms of the disease and learn to have time for themselves. These meetings showed situations of great emotional exhaustion, with feelings of guilt, shame and vulnerability and a great need to share personal experiences.

Such feelings became more intense in family members who still lived with the person with mental illness and there was also a greater interest and predisposition to participate in the meetings, compared to those who had their family member in a residential structure, with a life more independent of the family. This may be related to the objective burden related to the direct impact of the modifications and limitations imposed by the disease (disruption of domestic routines, restriction of social activities and work or financial difficulties) and subjective that translates into the set of feelings resulting from the intrapsychic experience of these limitations (loss, culpability, intra-family relational tension, concern for the future and fear of violence) (Xavier et al., 2002).

In 2018 GIRA participated as a trainer in the Training Actions "Caregivers in Network", within the scope of the Mental Health Nucleus, of the Social Network of Lisbon. This training for relatives of people with mental illness aimed to promote mental health, quality of life and the creation of mutual aid groups, having originated the Mutual Help Group of Benfica, territory where GIRA operates.

GIRA has also sought, over the years, to involve families in various events of the organization (e.g. Parties, Celebrations, Shows, Tours, among others), seeking their participation and involvement in the dynamics of the institution and in the life of their relative. It has also promoted the participation of families in initiatives of other community partners (e.g. Mental Health Walk, fighting stigma and defending rights), intending to give voice to people with mental illness and their families. At the same time, it has sought to listen to families in matters of mental health, calling for their participation in scientific studies and opinions on policies in this area, always with the aim of defending the rights of people with mental illness and their families; and seeks to disseminate and inform about Scientific Conferences and Meetings, calling for their active participation.

Finally, GIRA discloses projects and other support that families can enjoy, through partnership with other entities (e.g. psychotherapeutic support, mutual aid groups, etc.), always with the aim of responding to their needs.

#### 2.4. The intervention

At the level of intervention, with the referral processes being made directly to the institution, GIRA regularly receives contacts from families looking for answers in the community, with great difficulty in accessing information and integrating their families, given the scarcity of vacancies in the area of mental health.

As a rule, it is the social worker of the institution who makes the service (telephone, written or face-to-face) and seeks to give information, guide and evaluate the situations, seeking to integrate in the most appropriate response, within the institution; or refer to other responses, support groups, among others. In this welcoming of families, whenever possible, we seek to listen and support them in their difficulties, considering the family as a key element of the recovery processes of users.

GIRA bases its intervention on the community model of intervention where the participation and self-determination of the Person with Mental Illness is evidenced, intervenes in the area of psychosocial rehabilitation, defined in 2001 by the WHO as: "a process that offers individuals who are debilitated, disabled or disabled due to mental disorder, the opportunity to reach their potential level of independent functioning in the community, which involves both the increase of individual competencies and the introduction of environmental changes [...] The main objectives are the emancipation of the user, the reduction of discrimination and stigma, the improvement of individual social competence and the creation of a long-term social support system" (WHO, 2001, p. 77).

It also focuses on personal recovery defined as "a deeply personal process of rediscovering a new sense of identity, self-determination and personal empowerment to live, participate and contribute to the community" (Duarte, 2007, p. 127) and seeks that its practices are oriented towards recovery: with an orientation to the person and focus on their abilities; involvement of the person in planning, implementation and evaluation of services; self-determination and the ability to choose; potential for growth and hope in the future (Farkas et al., 2005).

Within the scope of its intervention it uses as its main work instrument the PIR – Individual Rehabilitation Plan, elaborated with the person and focused on their potential to overcome the obstacles, not leaving aside all the surroundings, in a holistic perspective.

The family presents itself as a resource and partner, being a fundamental element in this process, seeking a close follow-up of the reference technician of the user with the family members or significant people, so that they are involved and actively participate in their rehabilitation process.

This monitoring is done through regular contacts, meetings, promotion of outings and moments of leisure of the users with the families, making the family as an ally in the recovery process. Always aiming at the autonomy and life, as independent as possible, of the person with mental illness, according to their circumstances, needs and aspirations.

As mentioned earlier, the intervention is person-centered, but taking into account the person as a whole and, as such, in their relationship with the family and social support network, as well as with the community. In this interface between the various elements, GIRA articulates the intervention with the different services of the community: social, labor, cultural and/or health, namely with the mental health services, through the reference technician who centralizes all the articulations, which contributes to the success of the intervention.

#### 3. Family Associations

Family associations such as GIRA have emerged since the 90s, as a result of the pressure of the deinstitutionalization of people with mental illness, with the closure of psychiatric hospitals, and the need to create responses in the community or other alternatives for families who often found themselves unable to adequately support their relatives and who could not find public answers for them.

Driven by these needs and often with the support of mental health professionals, family associations were created, constituting themselves mostly as private institutions of social solidarity and developing social responses that became possible with Law No. 36/98 and Joint Order No. 407/98 and that brought important advances in the organization of mental health services.

Despite the creation of these associations and their growth at the national level, there was no joint work, which was reflected in the invisibility of families in the area of mental health and a small strength or representativeness in the organs and consequently in mental health policies, and the reduced participation of users and family members identified as a difficulty in the National Plan for Mental Health 2007-2016.

It should be noted that in 1997 the National Federation of Entities for the Rehabilitation of the Mentally III – FNERDM was established, which is a Private Institution of Social Solidarity (IPSS), which brings together 24 public and private entities of social solidarity that are dedicated to the Psychosocial Rehabilitation of people with mental illness, being distributed in 10 districts.

The following objectives stand out, among others: representation of the associated entities and participation in official bodies, commissions and working groups; debate of policies and measures aimed at the social integration of people with mental illness; encouragement of the creation of community rehabilitation responses; and support for the development of NGOs, users, family members, self-help groups, and the movement to defend the rights of people with mental health problems (*advocacy*).

This federation was constituted, for many years, as the only National Network that represented rehabilitation institutions and defended the rights of people with mental illness and their families. Although not all the members were associations of families, they were quite representative.

Over the last few years, FNERDM has increased its visibility and influence, having participated in different working groups within the scope of national policies for mental health, as well as with regard to the social inclusion of people with mental illness, fostering work in partnership and establishing an involvement with these same groups.

In September 2002 the FNAFSAM (National Federation of Associations of Pro-Mental Health Families) was established, being an organization project in a national associative model that brought together families of people affected by severe and persistent forms of mental illness. Its objectives were the cooperation between family associations and their representation at national and international level, to support, defend and promote the rights and quality of life of people with mental illness and their families. This federation functioned until 2007/2008 highlighting its participation in Congresses, scientific studies, publications for family members and representation in national bodies, however due to its inactivity, it failed to meet its objectives.

It is on March 31<sup>st</sup>, 2015 that FamiliarMente, the Portuguese Federation of Associations of Families of People with Experience of Mental Illness, is created, a non-profit organization of national scope, consisting of a set of Associations of Families of People with Mental Illness, based in various regions of the country. It currently has representatives of Family Associations from various regions of the country, excluding the Algarve, because in the region there was no association of families.

It arose on the initiative of a group of leaders of Associations of Families of people with mental illness, by the need for the families of people with mental illness to have representation at the national level, before the organs of sovereignty; to be able to exercise the right to participate, through organized and collective expression, in the defence of their rights and legitimate interests. Its purpose is to contribute to the implementation of measures that contribute to the improvement of the quality of life and well-being of families and people with experience of mental illness.

The National Federation Is Familiar and in accordance with its objectives not to create direct responses to families, but through associations to identify needs and reach out to policy makers to develop strategies or measures to address these needs. Its main role is to represent families in the defense of their rights, interests, promotion of mental health, the fight against stigma, dissemination of good practices in mental health, the creation of more family associations, as well as to promote the associativism of families in order to create an increasingly growing and more representative movement of families.

In pursuit of its objectives, FamiliarMente collectively represents the associations of families of people with experience of mental illness federated in it, before the Government, the Assembly of the Republic, other organs of sovereignty and the State, in public and private organizations, at national and international level, with regard to its scope of action.

It is a member of national advisory bodies in the health area, at national level (National Council for Mental Health) and regional (Regional Councils, where regional plans are drawn up and projects and programs are to be implemented according to the needs of families) and internationally is a Member of EUFAMI (European Federation of Associations of Families). In 2017 she was elected by the assembly of the republic to the national health council, within the scope of this council has already participated in the realization of two studies.

Finally, FamiliarMente's perception of the current situation of mental health in Portugal and the main concerns of the family associations that it represents, after listening to the current President - Dr. Joaquina Castelão are listed in the following table:

Struggle of families	Needs	Obstacles	Solutions
ut life and on	Vacancies in psychosocial rehabilitation responses	There are only 1400 seats nationally. Insufficiency in view of the prevalence of mental illness. Regional asymmetries.	Increase in the number of vacancies Regional distribution Creation of residential structures, for those who do not have the capacity to manage their own life.
Continuity of Care throughout life and Deinstitutionalization	Adequacy of existing legislation, rehabilitation responses	Referral process, family contribution, form of financing of the entities and length of stay.	Paradigm shift.
inuity of Ca Deinstit	Local mental health teams	Only 40 teams have yet been created at national level.	Need for 300 teams for greater monitoring of people with mental ilness and families.
Conti	Presentation of results	Lack of information on the integration of users that are accompanied by the responses.	Monitoring: how many users have returned to independent living, how many have returned to the labour market.

Table 1

Family associations have supported families through their direct involvement in the organization of services, developing residential and occupational social responses, vocational training or employment (insertion companies) and other projects and services for families, such as the creation of mutual aid groups, psychoeducation groups, training, among others.

These associations are often created within hospitals, with psychiatry and mental health services, supporting families in the search for community answers and clarification/information. On the other hand, the Casa de Saúde de São João de Deus and Irmãs Hospitaleiras (Care centers in the

area of psychiatry, mental health and psychosocial rehabilitation created by religious orders), are pioneering hospitable orders in the provision of mental health care and have also boosted the development of associations of families that usually provide more informal support, advising and mentoring the families of people who are supported by these services.

Other associations, such as GIRA emerge from civil society and create typified social responses to give direct support to their families with illness, creating the resources they sought in the community and responding to the needs of the territory and needs not covered by the State.

#### 4. Responses for families in the public service network

In mental illness historically families were considered as part of the problem and it is in the late 40's that the relatives of people with mental illness become the object of investigation due to the criticisms of the system, parallel to the new knowledge about mental illness. With the departure of patients from hospitals, new theories emerge to understand the difficulties of families with these patients, especially in the acceptance of the disease (Moreno & Alencastre, 2003).

In the 50s and 60s, family members began to live more closely with their loved ones who suffer from mental illness, which generated many difficulties in the family relationship and consequently consecutive hospitalizations. Families come to be understood as a whole, a system with a specific functioning and communication that needs to be modified thanks to the suffering of the patient, and this past to be seen as a carrier of the difficulties of family dynamics (Moreno & Alencastre, 2003).

It is widely accepted that family relationships are modified when a family member presents some health problem and that the inclusion of the family in the treatment of people with mental health problems is strongly associated with improvements in the patient and family dynamics (Souza, 2011). On the other hand, when the patient cannot achieve the autonomy necessary for an independent life, the family is a fundamental support, but with a huge wear and tear and reduction of his social life; it is therefore necessary to find ways to support families so that they continue to play the role of caregivers, without impeding the movements of autonomy, with an excessively protective attitude (Fazenda, 2008).

Families need to learn about the disease, treatment, ways to collaborate with the mental health team; community rehabilitation resources and services; they need to talk about their experience; sharing the burden of responsibility with other families; and be heard in their opinions. There are several answers in this sense ranging from counseling to family therapy, psychoeducational approach, self-help groups or family associations (Fazenda, 2008).

General hospitals or, still existing, psychiatric hospitals organize psychiatry services, with differentiated functional units, such as: acute hospitalization, community teams, liaison psychiatry (with other specialties), day units, psychiatry urgency or forensic psychiatry. They can also organize rehabilitation services, according to the needs of the territory.

However, with regard to families, there are no specific typified responses in public services, and each hospital is responsible for organizing psychoeducation, multifamily or other therapeutic groups to support the relatives of people with mental illness, taking into account the professional body, theoretical references and/or the families' own needs.

Citing Fazenda (2008), the psychoeducational approach appears in the 90s following studies by authors such as Hogharty, Anderson and others who verified the influence of social, environmental and family factors on the evolution of mental disorders. For these authors, this psychoeducational approach, through sessions with the family and the patient and joint sessions for several families, aimed to establish a therapeutic alliance with the family, the reduction of the negative emotions expressed and the reduction of the patient's relapses. Another author McFarlane has another perspective that he calls the Psychoeducational Multifamily Group and that aims to promote the collaboration of the family in the treatment, provide information about the disease, increase the social support network and prevent relapses; alerting to the stigma and social isolation of the family, resulting from the loss of social support network.

For a better understanding of the functioning of the family groups developed within some hospitals in Lisbon (e.g. Hospital de Santa Maria and Hospital S. Francisco Xavier) and their impact on families, Dr. Paula Godinho (Psychiatrist, Team Leader of the Day Hospital, a pioneering psychotherapeutic unit in Portugal in the development and study of intervention in Multifamily Psychoanalysis) was consulted.

Although each multifamily group has its own specificities, we summarize the functioning of this group, as well as its perception of obstacles to independence and mental health problems, in the following table:

Referencing	Attending physicians, physicians from other locations, other professionals and self-referral.		Relationship difficulties, illness throughout the family, prolonged suffering, family traumas and unresolved situations (transgenerational issues, war trauma, alcohol, etc.), young people leave home later and later.
Goal	Conversation group, in which dialogue is fostered to help people in suffering.	Problematic	
Periodicity and Duration	Biweekly sessions of 2 hours.		
Participants	Technical team, trainees, patients and families. The patient must always be involved. People outside the family nucleus can participate.	Obstacles to the	Very strong connection and an almost veneration to families; the lack of autonomy of young people and, in general, the lack of subjective and objective autonomy (interdependence) and the lack of support conditions, associations and structures.
Intervention Methodology	The proper conduct of the technicians generates a climate of trust so that they develop the ability to talk and listen to each other.	independence process	
Findings	Becoming aware of things that are done automatically and not realizing the impact; see other perspectives and learn to think with the help of others; What seemed to have no understanding happens to have (natural reaction and stress reactions). Greater autonomy and healthy interdependence.	Urgent mental health problems in Portugal	Development of an approach to mental pathology that is not only pharmacological; a comprehensive approach to the family, not just a focus on the patient and the medication; breaking ideologies: mental pathology has a cure – to demystify; families must be supported to transform relationships with family members; hopeful view of mental pathology; Psychosis or another illness can be an opportunity to improve the life of the family.

Table 2

Some of these data can be corroborated by a study on families in the European context (Torres et al., 2004) in which it is revealed that for people living alone the countries of Southern Europe (Italy, Spain, Portugal and Greece) contrast with the values of the Scandinavian countries and the North and Center, with Scandinavians living almost three times more people living alone than the South as a whole, This highlights the early independence of young Scandinavians from the rest. They point out that this can be explained by cultural factors, the existence of social support and even economic reasons. The South has the highest percentage of couples with children (51.4%) and of the smallest of couples without children, which shows, in another way, that in the South children are more likely

to stay at their parents' home. It also reveals that the countries of the South present, in a global way, the lowest household incomes in Europe and fewer alternatives of support and available social equipment and resources, which is reflected in lower values in the synthetic fertility index.

Finally, the study reveals that in the South there are more couples with children, more single parenthood and greater experience with other family members, which shows greater existence of extended households. Portugal is the country that has the highest number of divorcees, and this specificity in this context was explained by several factors, including the high rate of female activity (Torres et al., 2004).

Having proven the association between family functioning and mental health problems and the family system being complex and formed by several constructs: family functioning, family dynamics, family satisfaction, parenting practice and styles, and family support, all these factors can be predictors of increased difficulties in the relationship and functioning of these families.

In the end, Dr. Paula Godinho presented as urgent problems in mental health in Portugal: the need to develop an approach to mental pathology that is not only pharmacological; a comprehensive approach to the family, and not just focus on the patient and their medication; breaking ideologies: mental pathology has a cure – it is necessary to demystify; families must be supported to transform relationships with family members; a hopeful view of mental pathology is urgent; and psychosis or another illness can be an opportunity to improve the life of the family.

It should be noted that in addition to multifamily groups there are other psychoeducational interventions in other hospitals, with a view to the knowledge of the diseases by themselves and their families, ways of dealing with the symptoms, their prevention and adherence to treatment, such as the Psychiatric Hospital Center of Lisbon (CHPL), Garcia de Orta Hospital, among others.

Finally, the social services of hospitals and other local mental health services also play a key role in supporting families at the individual level through information and clarification of doubts, referral or referral to local resources, emotional support and counselling.

It is possible to understand that a healthy family dynamic is associated with a protective factor in the development of psychiatric diseases and that intervention in the family decreases their stress levels, encourages positive interactions and is directly associated with the success of the rehabilitation process of the person with mental health problems (Souza, 2011). It is therefore necessary to continue to invest in this support to families, promoting spaces for information, sharing and learning; increasing their social support networks; and giving hope, breaking protective habits and finding strategies for the autonomy of their relatives with mental illness.

#### 5. Conclusions

The evolution of mental health in Portugal and the paradigm shift to a community intervention model allowed users and families to take a more active role in defending their rights, no longer having a passive role as a recipient of services, to participate in the entire rehabilitation process and to represent themselves. This process has been, however, slow and difficult, but in recent decades they have begun to organize and have a voice, giving their opinion on mental health services and policies.

Civil society played an important role in the 90s in the implementation of psychosocial rehabilitation services in the community, creating structures and support services for people with mental illness and their families, made possible by the publication of the Mental Health Law No. 36/98. Families were often at the genesis of these movements, the result of the pressure of the deinstitutionalization of psychiatric hospitals and new ways of looking at the disease, with the evolution of psychotropic drugs, the human rights movement and criticism of the asylum and hospital model.

Many of the responses created remain to this day and continue to constitute the main direct support to families and users in the area of rehabilitation and social integration. It was evident that the Community Psychiatry model could contribute to the improvement of patients' living conditions and came to be organized as a diversified and interdisciplinary care system, which ensured the continuity of treatment in the community (Fazenda et al., 2022).

With the changes in the legislation of the Accompanied Adult Regime (Law No. 49/2018 of August 14<sup>46</sup>) with a paradigm shift, with regard to the exercise of the rights of people with mental illness, acceptance of the choices, wills and desires of oneself and choice of companions; and the most recent Mental Health Law (Law No. 35/2023) that enshrines the rights and duties of people in need of mental health care and regulates the restrictions of these rights and the guarantees of the protection of freedom and autonomy, the participation and vision of people with mental illness is now considered, favouring their rights.

On the other hand, the Statute of the Informal Caregiver (Law No. 100/2019) in which every caregiver has the right to the monitoring and training necessary for the provision of care, as well as to be informed about the evolution of the disease of the person cared for and the support they can have; to rest periods; and to participate in self-help groups, created in the health services responsible for their follow-up. It seems to be moving towards the recognition of the role of families and the burden associated with this type of disease, facilitating access to the support they need.

<sup>&</sup>lt;sup>46</sup> It allows any person who, for reasons of health, disability or behaviour, is unable to exercise his rights fully and consciously or to fulfil his duties, to apply to the Court for the necessary accompanying measures.

We cannot fail to mention the important role of family associations, federations and mental health services in this paradigm shift and that there is a long way to go for the laws to be substantiated in models and practices of effective participation of users and their families and in the provision of diversified services appropriate to their needs, "The levels of involvement and participation may vary according to the degree of commitment and responsibility assumed by clients and family members: Receive information about their diagnosis, the treatments and services available, their characteristics and long-term implications. Have an active voice in making decisions about treatment and rehabilitation plans. Participate in meetings or groups of planning, evaluation, research, training, commissions in partnership with public services. Do *advocacy* for the defense of rights and fight against stigma. Exercise control over decisions at the political level, planning, allocation of resources and budgets, location of services." (cit in Fazenda et al., 2022).

In short, it is up to everyone as a society to give voice and listen to people with mental illness and their families and bring them out of the invisibility and oblivion to which they were vetoed several decades ago. It is up to everyone to support their empowerment and self-determination, support in their role and consider families not only support, but partners in this path that is the quality of life and independence of people with mental illness.

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## II.C - FAMILY ORGANIZATIONS IN THE COMMUNITY OF ROME

## Content

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## 1. Introduction: Methodological choices and types of services offered.

Solaris Odv (volunteer organisation) is an association of family members and persons with severe mental suffering that was founded in 2002 to respond to a specific problem: how to guarantee a prospect of social reintegration to their relatives, who are about to leave the therapeutic communities, in a social context still lacking adequate services. In cooperation with the local Mental Health structures (CSMs and therapeutic communities) in the territory of the Department of Mental Health (DSM)) of ASL Roma 1 (see first report -Italy) and with those of the local government (II Municipality of Roma Capitale), a "supported living" project was launched, enabling users leaving communities or family homes, to go and live in autonomous flats rented on the market, choosing the people with whom they are going to live.

The specificity of this origin gives Solaris some special characteristics:

- The family members who are part of it are active in the first person and protagonists of the activities that the association carries out, starting from the centrality, needs and choices of the users;
- From the outset, there has been a close bond of collaboration between family members and operators of territorial Mental Health services.
- From the outset, cooperation is established with local government structures that guarantee financial support for home care.

## These characteristics mark the methodological guidelines and types of services that the association will subsequently develop.

In fact, with the transformation of psychiatric care systems and in particular with the end of the asylum regime in Italy, families have assumed an indispensable role in Mental Health Care paths. Faced with this new position, psychiatry has reacted with diversified positions, giving rise to partly divergent directions. Especially in the United States, an orientation centred on a pathogenic role of the family from whose disturbed relationships the patient had to be freed initially prevailed. However, there is an orientation that tends to consider the family as a resource in care paths. Driven by the spontaneous initiative of family members, they begin to be identified as caregivers and organise themselves into associations that promote lobbying activities, submitting requests for more public resources, claiming the right to have a say in the organisation and planning of services, or, more recently, giving rise to autonomous care organisations alongside the public ones. Family members, therefore, fifty years after the closure of asylums, at least formally, are no longer seen as the "accomplices" in a process of marginalisation and segregation of patients, they tend to be perceived by the institution as a "resource" and tend to position themselves as active subjects, and not just bearers of claims. However, there are still profound ambiguities and prejudices with regard to family members, requiring a continuous redefinition of power relations between institutions, family and users.

In this context, Solaris has from the outset focused on the valorisation of family members and the centrality of the family/user nexus.

# 2. Services to family members

## 2.1 Active involvement of family members:

Solaris promotes the centrality and protagonism of family members by enabling them to participate in the planned activities and by enhancing their skills. Family members turn to Solaris for different reasons that often cannot be fully defined, either because they are directly related to users who are followed by Solaris in supported living or because they are looking for answers to cope with the situation of a relative who is not followed by Solaris or because they need advice and support.

People who contact the association are offered this path:

- an initial information interview (in person or by telephone) on the association and its activities and any information they require is provided;
- If they intend to deepen their relationship with Solaris, they will have an interview with a volunteer psychotherapist, now retired, who runs the association's psychological desk and has worked in the local Mental Health services. The interview serves to clarify better the family member's expectations, their skills, and their possible interest in collaborating with the association.

Based on the expressed intentions, family members are offered the opportunity to participate in a wide range of activities already being carried out or to possibly propose new ones.

 Workshops, and socialisation activities for users and open to operators, volunteers and interested family members.

The workshops are of two types:

1. <u>Permanent</u>: these are a number of workshops that have been running for many years and have shown great appeal to participants. They arose thanks to the presence in Solaris of some family members with specific skills or experienced users. These are the Journalism workshop coordinated by two family members, Repubblica journalists; the free-writing workshop coordinated by an expert user; and the workshop on gardens, which, although its methods have changed over time, focuses on the search for a different relationship with nature. The workshop is coordinated by a family member, a botanical expert; the computer workshop is coordinated by a volunteer, a computer engineer.

These workshops are based on the principle of 'doing together' and on the realisation of tangible products that make it possible to "measure" the importance of the path taken.

2. <u>Not Permanent</u>: These are workshops linked to the realisation of temporally defined projects, or born in the wake of a proposal by a family member or a user or operator. (Art, role play, relations with schools, etc.).

#### Communication activities

Communication is a very important area for the involvement of family members, users, volunteers. It finds its elective background in the workshop activities, in the presence of experienced family members able to guarantee the quality, even graphical, of the results, and in the widespread expressive skills present among the users and family volunteers. These activities are coordinated by a board consisting of a professional graphic designer family member, a volunteer journalist, a junior graphic designer, and an IT expert. The board coordinates and enhances the "choral" contributions of family members, users, and volunteers, enabling the production of the quarterly magazine "Pausa Caffè", a well-structured website, a Facebook page, and numerous publications. (The materials produced are highly visible tools in public initiatives, book presentations, and web communication). Many family members and users are also strongly rooted in the territory and constitute an important channel for circulating information and "taking care" of relations with the various territorial authorities.

## • Project drafting Activities

Project drafting activities are a very important area in the involvement of family members. The activity itself was born from the presence in Solaris of some family members with professional research and project drafting skills. This has made it possible to set up a committee that coordinates activities and, that on the basis of project drafting choices, has been involving a number of young volunteer researchers and from time to time family members and experts, to carry out specific projects. The committee is made up of two family members, who are sociologists, an IT volunteer, a family member who is an expert in European projects, and a junior researcher. The project drafting group permanently involves another eight people including family members, volunteers, and operators.

## Office management

Office management is usually one of the first activities in which family members are involved, the most immediate and continuous activity. Management involves several activities:

1. The physical opening of the office according to a set schedule and timetable and on the basis of a rotation of persons. This activity involves answering the telephone, greeting people seeking information by offering them basic indications, making any appointments, picking up parcels or mail, welcoming and facilitating the activities of Solaris members who come to the office for meetings and tasks, and regulating the various presences to avoid creating confusion.

2. Contributing in a planned manner to the material organisation of events, outings, collective lunches and dinners. Ensure access to the office and its usability for meetings, workshops and scheduled events.

This set of activities involves users, family members, and operators in a "doing together" in which one is free to express one's abilities and favours a different way of building relationships, which lose the rigidity and hierarchies linked to roles (the parent, the child, the user, the expert, the operator, etc.) and become equal, opening the way to important changes in personal relationships as well.

#### 2.2 Training and support services

Solaris provides training for family members so that they can best contribute to the reintegration and independence of their relatives and offers a psychological support service, starting from the principle that family members are both protagonists and sufferers.

## 1. Training

Three types of training are provided:

- 1. The direct observation method. It is a method developed by the psychiatrist Francesco Scotti who, through an articulated observational path, teaches how to grasp the meaning of observed relationships without judging, maintaining the right distance allowing the observer to grasp what is not immediately explicit and hidden from a judging look. The path involves the observation of a specific relational context that is repeated over time, the drafting of an observation protocol to be discussed in the reference group, and the return of the observations to the observed context. The objective is to "educate" those who participate to look at the world and specifically at relationships with relatives, acquiring the "right distance" from pain and the balance necessary to deal with the complexity of these relationships. The program is coordinated by an expert psychotherapist and takes place fortnightly.
- 2. Theoretical/methodological training. This consists of a monthly discussion between the members of the Solaris association (users, family members, operators, volunteers) and a psychiatrist, a scholar of Recovery developments and its concrete applications, and the creator of the Supported Housing experience from which Solaris was born. The specific difficulties encountered by the participants in the course of their activities are traced back to a more general frame of reference that enables participants to broaden their interpretative skills and knowledge.
- 3. <u>Orientation to the management of the office</u> for people who intend to collaborate in the management of Solaris activities, a short training is planned so that they are able to provide basic information to those who contact the association, both by telephone and in person.

#### 2. Support

The Psychological Help Desk is a service carried out by a volunteer psychotherapist with long experience in territorial Mental Health services and offers different services:

- The help desk contributes to deepening initial relations with family members who turn to Solaris, outlining with these people the interests, needs, and expectations that prompted them to contact the association.
- The help desk offers psychological support to family members who need special support in difficult times.
- The desk is however open to users and volunteers who need support in times of difficulty.

The service is weekly and takes place at the Solaris office.

## 3. Services to the users

Families and people with mental suffering are closely interconnected even in cases where this connection is denied by one or both parties, and even in the case of nonexistence of the family. Care paths must therefore deal with this connection. In this sense, the report tries to explain not only what Solaris does in supporting family members as an active component of the care paths, but also what interactions and consequences the services, specifically aimed at users, produce on the family members, starting from the evidence that the users' paths, their progress, moments of crisis, their growth and independence constitute a central component in the lives of those connected with them. This is particularly important in the case of Solaris, which from the outset is made up of family members who organise themselves to offer their loved ones the possibility of a socially integrated and independent life.

The core of these services is a path called Supported housing. This path starts from the assumption that having one's own living space, a "home", is a fundamental need and right of everyone, and that satisfying this need is a central element in the treatment of mental suffering. You don't learn to live gradually by doing exercises of different difficulties as you do with a fracture. One learns to live by living. On the basis of these assumptions, in 2002, thanks to the cutting-edge psychiatrist Antonio Maone, willing collaborators and operators, and a group of family members, people starting to leave the therapeutic community were offered the possibility of going to live in autonomous flats with one or more people choosing each other.

In this path, the Mental Health Centre (CSM) provides clinical support, Solaris through its operators provides home care to support users in the difficult task of regaining everyday acts, and the II Municipality provides financial support for home care.

The path of supported housing implemented by Solaris presents a very important peculiarity also in a perspective of reproducibility of the experience. In fact, within the framework of the supported housing services currently existing in the ASL Roma 1 area, the contribution and services that

Solaris practices have as protagonists the family members not only as individuals but also as an association and this allows them a space, a role and the possibility to influence the care guidelines that family members as individuals do not have.

This path has been extended by Solaris with the organisation of multiple socialisation activities (which were previously mentioned) financed by ad hoc projects or the voluntary work of many family members.

It should also be borne in mind that the involvement of family members in supported living pathways goes far beyond formalised activities. Their contribution is crucial in the lives of many users, reaching where institutional services and operators are unable to arrive due to different constraints (economic, organisational) often coping with unforeseen events, discontinuities in the behaviour and paths of suffering people and serious emergencies.

At the same time, supported housing services have an important impact on family members. They constitute in fact:

- An important support to concretely building the process of detachment of children from their families and of family members from their children
- A perspective of care that in the practice of living teaches how to deal with the uncertainties, the relapses of mental suffering, knowing that there is a known and experienced support network (institutional and associative)
- A reduction of responsibilities that are shared with the various contributors to care paths
- A chance to see their relatives regain possession of their lives

This service, in short, helps family members to recover their own dimension of life that does not depend exclusively on the illness of their children and confirms in practice how what often appears to be a personal problem cannot be solved except through a collective dimension.

# 4. The Networking

Networking plays a central role in enhancing the independent living paths of users and in valuing the role of families. This is the weaving of networks that primarily involve family associations and may be local or national in character. In these paths, however, subjects not necessarily linked to the field of mental health also assume great importance, as they make it possible to expand opportunities for socialisation by opening up new experiences and new possibilities of knowledge. In particular:

#### 4.1 Local level

Solaris has contributed to building a network of family and/or volunteer associations and social cooperatives working in the field of mental health and disability more generally. These include:

- Solaris Supported Housing, Social Cooperative S.r.l.;
- Arap, Association for the Reform of Psychiatric Care;
- Insieme con te, Mental Health Volunteer Association;
- Associazione Fenice Lazio ODV, Volunteer Association;
- Apeiron (Cultural Association for Psychoanalytic Research);

- Spazio Comune, Association for Social Promotion;
- Prassi e Ricerca Social Cooperative, partner of Solaris in the home care project;
- Scalea93 (Mental Health volunteering);
- Insieme con te (Volunteer Association);
- Tininiska Italia aps (Social Promotion Association).

Solaris is part of CESV (Volunteer Service Centre), which acts on a regional level and coordinates volunteer associations operating in Lazio.

A network of associations and social cooperatives external to Mental Health:

- ACAB, Cultural Association Antonello Branca;
- I Senzaterra, Association for Social Promotion for the dissemination of musical culture;
- The old Scull, music-video performance
- Asinitas Onlus, Volonteer Association
- Tra noi, Moral Organisation
- Com Nuovi Tempi/Confronti, Magazine on religion, politics and society
- Associazione Amici di Villa Leopardi, Association Friends of Villa Leopardi
- Studio di Architettura del Paesaggio Uptown Muse, Uptown Muse Landscape Architects

#### 4.2 National level

The local activities of family members find an important reference in some national networks of associations, including:

- UNASAM National Union of Mental Health Associations, of which Solaris is a member, is the most important national network of Mental Health Associations with 70 Associations working in all regions of Italy;
- National Coordination of Mental Health:
- ANFASS National Association of Families and Persons with Intellectual Disabilities and Neurodevelopmental Disorders.

Their existence strengthens the political/institutional impact of the organised presence of families and enhances the possibilities for national mobilisation such as the realisation of the National Mental Health Conference convened by the Ministry of Mental Health in June 2021, the participation in the Technical Table for Mental Health set up by the Ministry of Health in January 2021, the National Demonstration for Health in June 2023.

## 5. Institutional relations

The Solaris association works closely with:

#### 5.1 Local Mental Health Services

The Solaris Association works closely with the local Mental Health Services of the II District of the Department of Mental Health (DSM) ASL Roma 1, in particular the Therapeutic Community of via Sabrata, the Mental Health Centre (CSM) of via Sabrata, and with the II Municipality of Roma Capitale. The history of the Solaris Association makes it possible to "measure" the importance that institutional relations have in the social reintegration paths of users, and the importance that the contribution of family members has in these paths. The orientation that local Mental Health Services and government institutions take towards them appears decisive, and is mainly oriented towards considering family members as active subjects to be directly involved.

## Among the modes of involvement:

- the establishment of multi-family psychoanalysis groups at the CSMs of the Rome 1 DSM. This approach originates from the thought and experience of Jorge Garcia Badaracco, an Argentinean psychiatrist and psychoanalyst, who worked in the 1960s in the psychiatric hospital in Buenos Aires. The groups are based on an open and free dialogue between the participants based on three simple rules: 1. each participant speaks one at a time on a topic chosen by him/her and the others listen without interruption; 2. no opinion is considered "right" and all participants are invited to listen and respect the point of view of others, even if different from their own; 3. participants raise their hand to take their turn to speak. The groups are open to all those involved in care path, family members, users and operators, on an equal footing, based on their own needs and experiences. They constitute an important reference point for Solaris and a very large number of family members and users.
- the Protected Home Care (ADP) which represents a modality of implementation of the therapeutic project that the DSM has chosen as a general guideline and that the Mental Health Centre of territorial competence may choose to set up for psychiatric users with stabilised disorders and residing in a habitual home. ADP is aimed at maintaining personal autonomy and promoting social inclusion. The home care service is provided through accredited subjects, as in the case of Solaris Odv, and supports the user free of charge in regaining possession of daily life, strengthening his or her abilities and possibilities for independent living.

#### 5.2 The local authorities

The Solaris Association works closely with the Local Authorities and in particular with the 2nd Municipality of Roma Capitale, which has been financially supporting the Supported Home Care realised by Solaris for 20 years.

#### 5.3 Councils

Solaris is a member of three different councils:

1. Mental Health Council of the DSM ASL Roma 1.

The Council is an institutional body of the Department of Mental Health with an advisory character of which are members:

With voting rights

Family associations in the DSM territory

The representatives of the Scientific Societies of Psychiatry

The social policy councillors of the six Municipalities present in the ASL Roma 1 territory

The representative of the Municipality of Rome

As permanent guests

The General Director of ASL Roma 1

The Director of the DSM and other DSM representatives

- 2. City Council for Mental Health reporting to the Municipality of Rome
- 3. Council of Volunteers of the II Municipality to which the voluntary associations of the II Municipality belong and which is therefore not specific to Mental Health

## 6. Conclusions

The described situation is a situation with great potential, which however does not represent the prevailing condition in the Roma Capitale area and which is suffering serious limitations since the restriction of economic resources pushes the regional institution and consequently the territorial services to cut services and their diffusion throughout the territory.

In particular, the serious lack of personnel is affecting not only the quantity but also the quality of services to families and Mental Health in general.

It is in this context that associations like Solaris play a crucial role, especially in supporting family members.

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# CHAPTER III – GOOD PRACTICES OF AMAFE, GIRA AND SOLARIS FOR INDEPENDENT LIFE

The FILMI project was also born with the aim of disseminating the best experiences achieved by the three partners, as there is a widespread lack of information on the services and activities promoted by family associations, on the results they achieve and on their territorial impact.

Promoting the dissemination of the best experiences as Good Practices means attributing to these Associations a decisive role also in the field of community interventions, it means giving greater visibility to the positive things they achieve in the territory and not relegating the Associations to the shadow of the socio-health institutions and the family members only to the role of self-referential "supporters" of their more fragile relatives.

There are different methodologies used to define and select Good Practices in mental health, depending on the type of interventions and services that are examined; some interventions or services deserve more detailed and refined examinations, for others more agile and flexible tools and criteria are adopted.

After a careful examination of the documents disseminated locally and internationally on the web, to examine and evaluate their own experiences and report the best ones as Good Practices, the representatives responsible for this Report have adopted two documents already tested at an international level:

a) the evaluation criteria proposed by the OECD<sup>47</sup> to evaluate interventions that arise with humanitarian purposes;

b) a questionnaire developed by the Committee for Bioethics (DH-BIO) of the Council of Europe (COE) to collect information to develop a Compendium of Good Practices.

a)In 1991, the Development Assistance Committee (DAC) of the Organization for Economic Cooperation and Development (OECD) first established the criteria (relevance, effectiveness, efficiency, impact and sustainability) for evaluation of humanitarian projects, programs and policies.

After almost thirty years of their use internationally, in 2018-2019 the OECD DAC Network on Development Evaluation (EvalNet) revisited the definitions and use of these evaluation criteria, adapting the definitions of relevance, effectiveness, efficiency, impact and sustainability, and introducing a new criterion, coherence.

This Report on "Good Practices of Family Association Services for Independent Living" represents the results of the work of the three partners, who examined the services they offer in their territory on the basis of the six criteria and selected those that respond to the indications present in the new definitions of the criteria of relevance, coherence, effectiveness, efficiency, impact and sustainability (see Annex 1)

b)For the description of the selected good practices, the representatives of the three partners adopted a questionnaire developed by the Committee for Bioethics (DH-BIO) of the Council of Europe (COE) in 2019, aimed at collecting information to develop a " Compendium of good practices to promote voluntary measures in the field of mental health" 48.

<sup>48</sup> https://www.coe.int/en/web/bioethics/compendium-report-good-practices-in-the-council-of-europe-to-promote-voluntary-measures-in-mental-health-

<sup>&</sup>lt;sup>47</sup> https://www.oecd.org/dac/evaluation/revised-evaluation-criteria-dec-2019.pdf

The questionnaire<sup>49</sup> is aimed at the delegations and stakeholders of the 47 countries belonging to the COE and collects examples of the best experiences born in contrast to the coercive measures that the institutions of many countries still adopt.

The questions that compose it are not directly connected to the topic of coercive measures, therefore they represent an already tested path to collect the most significant information and describe the experiences that also arise in other areas of mental health.

The partners respected the division of the questions into two sections (essential questions and additional questions) and developed the synthesis of the Good Practices selected.

The main purpose of this 6 Good Practices are:

- Independence Training (AMAFE)
- Support and Strengthening autonomy (GIRA and SOLARIS)
- Sharing autonomy (SOLARIS)

<sup>&</sup>lt;sup>49</sup> https://rm.coe.int/inf-2020-5-form-for-collection-of-examples-of-good-practices-in-mental/16809efd00

## III. A- AMAFE GOOD PRACTICES

- 1. Introduction.
- 2. The methodology adopted
- 3. AMAFE Good Practices
  - 3.1. Project "Emancipation"
    - 3.1.1. Context and characteristics of the project *Emancipation*"
    - 3.1.2. Training Phase of the "Emancipation" Project
    - 3.1.3. Phase of gradual transition to independent life of the project "Emancipation"
    - 3.1.4. Good project practices "Emancipation"
  - 3.2. Project "Get started"
    - 3.2.1. Context and characteristics of the project Get started"
    - 3.2.2. Good practices from the "Get started" project
- 4. Conclusions

#### 1. Introduction.

One of the main objectives of AMAFE is for young people who face serious mental health problems to increase their personal resources to avoid making their experience chronic. To achieve this, we have different initiatives that seek to promote the personal autonomy of the participants, encouraging the construction of a satisfactory life project that motivates their recovery, growth and development.

This document aims to make the reader aware of the projects "*Emancipation*" and "*Get started*" carried out by the association, both framed within the area of training, education and support of the young participants, maintaining a comprehensive approach at all times, which seeks to cover the needs and resolve emerging conflicts in the personal and family areas and social of the beneficiaries

Both projects serve each participating person individually (considering their age, family situation, socioeconomic position, previous studies, etc.) and seek to link them to their family, academic and social environment so that the challenges of their own experience are addressed. at the service of the development of all areas of your personality.

## 2. The methodology adopted.

Both projects are similar in the population they target and in the objective of promoting autonomy and reducing the biographical rupture of young people who have experienced a psychotic break. However, the methodology developed in each project varies depending on the objectives, timing, training content and the evaluation process.

Broadly speaking, we highlight a comprehensive and socio-community methodology, which has a multidisciplinary professional team focused on offering, according to their scope of action, valuable knowledge for beneficiaries and their families.

Both programs establish two lines of action, one individual and the other group. Individual action is developed through interviews that young people carry out with the assigned reference professional. Group action takes shape differently depending on the project:

The project "*Emancipation*" brings together families with the objective of imparting knowledge in the areas of occupational therapy, psychology and social work, and applying it to the particular situations of each of the participating members.

The project "*Get started*" maintains a didactic group methodology where academic knowledge is taught that allows young people to return to formal education after experiencing psychotic episodes and that this can avoid possible isolation, reduce biographical rupture, reduce social stigma and self-stigma associated with psychosis, etc.

#### 3. AMAFE Good Practices

## 3.1. Project "Emancipation".

## 3.1.1. Context and characteristics of the project*Emancipation*"

The project "*Emancipation*" by AMAFE arises in response to a growing concern in society in relation to people facing serious mental health problems and living with their families. It is therefore a local project, framed in the area of training, education and support. These situations can create challenges for both affected people and their families, including possible care overload and difficulty developing an independent life. The main facilitating factor has been the collective awareness of the social base about this need discovered with special mention to the brothers and sisters of people with a mental health problem who are witnesses of these processes of chronic dependency between parents and children.

Although the activity is not linked to health intervention, it indirectly seeks to prevent the chronicification of codependency. The need for this project is justified for several reasons:

**Prevention and Autonomy**: The initiative seeks to intervene before dependency situations become chronic, empowering people with mental health problems to acquire skills and resources that allow them to lead an autonomous life.

**Strengthening Families**: Living with a person with mental health problems can test families in emotional and practical terms. This project seeks to support families in understanding the associated challenges and developing healthy support strategies.

**Improved Quality of Life**: By promoting independence and autonomy, the project aims to improve the quality of life of people with mental health problems, allowing them to achieve their personal goals and participate more fully in society.

**Preventive Approach**: Early intervention can prevent the exacerbation of mental health problems and reduce the risk of functional deterioration, thus improving the long-term prognosis.

AMAFE's "Emancipation" project is based on a structured methodology focused on the empowerment of people with serious mental health problems, with the aim of promoting autonomy and independence in an environment of family coexistence. The methodology is made up of two different but complementary phases:

## 3.1.2. Training Phase of the Project "Emancipation"

Duration of 9 months: This duration has been chosen to allow the time necessary for in-depth learning and consolidation of skills.

Small Groups: Each group is made up of a maximum of 6 family units, with the purpose of guaranteeing personalized attention and active participation of all members.

Diversified Training Contents: The training sessions cover three main areas: Occupational balance, psychology and social aspects. This includes managing daily activities, structuring time, emotional management, resolving family conflicts, and accessing community resources.

Scheduled Sessions: Sessions are held weekly, alternating between sessions for people with a diagnosis, sessions for families and joint sessions. This approach allows for individualized learning and a deeper understanding of family dynamics.

## 3.1.3. Phase of gradual transition to independent life of the project "Emancipation"

Gradual Transition to Independent Living:

After the training phase, a transition phase towards independent living begins for those participants who feel ready.

Personalized Home Support: During this phase, individualized follow-up is provided at home, allowing people to apply the skills learned in real-world situations.

Promotion of Family Support: The importance of maintaining a solid connection with the family as a source of emotional and practical support is highlighted, avoiding the establishment of new dynamics of dependency.

#### **Impact Indicators:**

- The success of the "Emancipation" project is evaluated through key impact indicators, measured throughout the training and emancipation phases.
- Perceived Level of Autonomy: Measured through self-assessment questionnaires that measure people's perception of their own autonomy in specific areas of daily life.
- Participant Satisfaction: Evaluation of the satisfaction of participants and their families with the content, sessions and support provided.
- Achievement of Monthly Objectives: Monitoring progress towards the objectives established at each stage of the project, with regular reviews and adaptations if necessary.
- Skills Development: Evaluation of acquired skills in areas such as time management, emotional management, problem solving and access to community resources.
- Transition to Independent Living: Monitoring the process of people's transition towards independent living and the ability to maintain this autonomy.

The collection and analysis of these indicators provide a comprehensive view of the project's impact, allowing for continuous adjustments and improvements to ensure that people with mental health problems and their families achieve a higher quality of life and autonomy on their path to independence. All this information is reflected in a final report.

## 3.1.4. Good project practices "Emancipation"

The project requires small work groups and a varied multidisciplinary team which, at first, would indicate high implementation costs. However, by emphasizing the autonomy of each participant,

seeking in the medium term the least possible professional supervision, and maintaining this independence over time, it is a cost-effective and cost-efficient project in the medium and long term. that transforms a future of 24-hour care and supervision into a much more self-managed, proactive scenario adjusted to the wishes and needs of people with a mental health problem. It reduces the need for highly technical residential units and constructively takes advantage of the family and cultural resources of southern European societies.

AMAFE's "Emancipation" project responds to the need to empower people with serious mental health problems and their families, promoting independence and autonomy. The justification is based on the prevention of dependency and the improvement of quality of life. The methodology, divided into training and emancipation phases, seeks to provide a comprehensive and sustainable approach for the development of skills and the promotion of well-being. The main barrier in the execution of this project has focused on the lack of financing. This situation of lack is already general in the social field of mental health, but you have been especially notable in this project given, on the one hand, its individualized approach, which makes its scalability difficult and, on the other hand, the absence of public aid to the This is a different intervention model than the existing residential units where the professional figure has greater weight. In view of the replicability of this project, we consider that joint work between diagnosed people, families and professionals is essential; on the other hand, a firm commitment from each participant is necessary to be able to change the dynamics of family functioning established for years. Finally, a multidisciplinary team capable of integrating their knowledge equitably since it is a complex and multifactorial intervention. Ultimately, the project aims to offer these people the opportunity to live with dignity and lead autonomous and meaningful lives.

## 3.2. Project "Get started"

## 3.2.1. Context and characteristics of the project Get started"

The project "Get started" by AMAFE began in 2018 and emerged as a response to the difficulties observed by the Youth Care service in young people who experience a biographical break after a psychotic event. It is implemented in the area of training and education, and is aimed at adolescents and young people who have experienced a psychotic break and have abandoned their training and educational process. It is not linked to healthcare, but rather addresses a situation of biographical rupture derived from a psychotic experience.

The general objective of the practice is to facilitate socio-community inclusion, prevent isolation and reduce the biographical disruption caused by psychosis. In addition, it seeks to reduce social stigma and self-stigma associated with psychosis, as well as establish contact networks between different devices to provide comprehensive treatment to young people with psychotic disorders.

In specific terms, the practice implements effective study techniques and guides young people towards a training itinerary, strengthening educational content for access tests to higher training cycles or degrees; In short, it seeks to recover and strengthen attentional processes, fill factual gaps derived from the training absence while developing social and relational skills.

The scope of practice is local, and is carried out through 30 sessions of 3 hours each, for a total of 8 weeks in the summer. It is divided into four days a week, with intervals of 50 minutes and 10 minutes of rest between each session. The pedagogical method used for academic content is teaching exposition, complemented by auxiliary interactive and discovery techniques. For applied workshops,

"Thematic Immersion" is used, which involves simultaneous dialogues, brainstorming and concept maps.

In terms of impact, the practice has proven to be transformative for both the young people and the educators involved. Participants have experienced notable improvements in their learning and self-confidence. Workshops on anxiety management, social skills, and study techniques have been effective in empowering students and improving their academic performance. The group work dynamic has encouraged personal growth and overcoming obstacles.

Professionals and participants highlight the restoration of hope and motivation in young people with mental health challenges. The practice has changed perceptions and attitudes, demonstrating the potential of resuming studies and achieving goals with the appropriate support. In short, the project exemplifies how education and support can make a significant difference in the lives of those facing unique challenges.

In conclusion, the "Get Started" project represents a holistic and effective approach to addressing the educational and developmental needs of adolescents and young people who have experienced psychotic breaks and have faced challenges in their educational process. Through a local approach and focused on socio-community inclusion, the practice has managed to transform the lives of participants by providing them not only academic skills, but also tools to face anxiety, develop social skills and regain motivation.

The use of pedagogical methods such as teaching exposition and thematic immersion have proven to be effective in the transmission of academic knowledge, in the interest and involvement of students, as well as in the creation of a cooperative and enriching learning environment. The continuous evaluation methodology and periodic written tests have contributed to measuring the progress of the students and reinforcing their commitment to the educational process, allowing them to act in time when any difficulty arose in the learning process and transversally addressing aspects of the students' self-concept. Students, demonstrating their ability to integrate new concepts and face challenging situations.

The positive impact of the practice is reflected in the academic and personal improvements observed in the participants, as well as the restoration of their confidence and hope for the future. The collaboration between professionals and participants has created a space of mutual support, where obstacles are transformed into opportunities for growth and achievement.

This project also highlights the importance of addressing mental health from a holistic perspective, recognizing that psychological well-being is intrinsically linked to educational success and personal development. By providing emotional and academic support simultaneously, "**Get started**" has demonstrated how combining approaches can generate transformative and lasting results.

Ultimately, the "Get Started" project serves as inspiration for other educational and mental health initiatives, highlighting the importance of empathy, professional support and the creation of an environment conducive to the growth and self-realization of the individuals who They face unique challenges on their path to success.

## 3.2.2. Good project practices "Get started"

In the project memory "Get started" It is expressed that this practice has transcended as a transformative opportunity for both the young people and the educators involved. Despite initial differences in academic skill levels, participants stood out with notable improvements in their learning, strengthening their self-confidence.

Workshops on anxiety management, social skills and study techniques have proven to be effective tools to empower students on their path to educational success, since through a rigorous evaluation methodology, we have been able to see an improvement in exams, papers and interviews carried out throughout by the young people. In addition, the dynamic of cooperative group work has created an environment conducive to personal growth and overcoming obstacles.

Both professionals and participants point out that the most significant transformation has been the recovery of hope and motivation in young people facing mental health challenges. The project has managed to change perceptions and attitudes, demonstrating that with adequate support, beneficiaries have the potential not only to resume their studies, but to achieve their goals and aspirations.

We could highlight that the factor that has facilitated the implementation of the practice is that the association has been developing a Youth Care service since 2015 that complements specific actions for people who develop psychotic disorders as well as their families. People

Different types of programs are developed within the Youth Care Service:

- Mental health
- Physical and Functional Health
- Cognitive processes
- Social and community functioning
- Vocation: training and employment

If we look at the successful transferability of this practice to another organism, it is necessary that we assess a series of essential factors. Firstly, if this project is to be transferred to another entity, it is important that there is a clear understanding of the practice and its objectives, so that it can be communicated effectively to the new entity.

Detailed documentation and the availability of manuals or guides that explain the process step by step can facilitate implementation in the new organization. Likewise, it is crucial to have adequate resources and capabilities, both human and financial, to ensure a smooth and successful transition.

In this sense, because the beneficiaries were already part of the association's care services, we can say that the project was designed with a high level of connection between professionals and students, which facilitated very strong adherence to the program, as well as high involvement, an (almost zero) absenteeism rate, clear and close two-way communication and a very high knowledge of specific needs.

If this practice could be transferable, we must assess the capacity for adaptation and flexibility to address cultural, structural and operational differences. These factors were reduced by previously

knowing the participants. Something that can reduce group differences and unforeseen events is to follow a rigorous interview process, where the items evaluated in the initial meeting meet all the requirements to assess a good connection to the project.

In short, the project "Get started" has shown that with good professional support, empathy and adequate opportunities, it is possible to create an environment where obstacles become springboards to success. Educators are proud of the dedication and enthusiasm of students, and young people have found a path to academic and personal self-actualization. This project exemplifies how education and support can make a significant difference in the lives of those facing unique challenges.

#### 4. Conclusions.

In a context where mental health and social inclusion are key priorities, the projects "Emancipation" and "Get started" from AMAFE shine as inspiring examples of how to address unique challenges with comprehensive and transformative approaches. These initiatives have proven their worth in empowering people with serious mental health problems and their families, offering tangible solutions to improve quality of life and promote independence. Both projects transcend the traditional limits of intervention, channeling efforts towards training, education and emotional support, while directly attacking the social stigmas associated with mental health.

The project "Emancipation" stands out for its preventive approach and its ability to prevent the chronicification of codependency. By providing a space for learning and support, it not only encourages the autonomy of affected people, but also strengthens families in their understanding and management of emotional and practical challenges. This project challenges the traditional notion of care and offers a transformative vision where independence and inclusion become achievable goals. Its structured methodology and focus on concrete impact indicators demonstrate a serious commitment to continuous improvement and results-based evaluation.

On the other hand, the projectGet started" highlights the undeniable connection between mental health and educational success, providing young people who have faced psychotic breaks with the necessary tools to return to their studies and overcome emotional and academic barriers. Through interactive pedagogical approaches and effective study techniques, this project has transformed participants' perception of their capabilities and restored their hope for the future. Its local and collaborative approach, along with demonstrated adaptability and flexibility, are essential to its success and the possibility of transferring this model to others contexts.

In conclusion, the projects "Emancipation" and "Get started" from AMAFE embody the idea that education, emotional support and inclusion can have a transformative impact on the lives of those facing unique mental health challenges. These initiatives demonstrate how empathy, engagement and creativity can make a difference by offering development and empowerment opportunities to individuals and families, while challenging and transforming limiting social perceptions. By exploring new ways of addressing mental health and inclusion, these projects inspire others to follow a similar path, encouraging positive change in society at large.

## III. B- GIRA'S GOOD PRACTICES

#### 1. Introduction

## 2. Good Practice 1 – Autonomy Support Residences (RSA)

- 2.1. Phase A: Preparation and Involvement
- 2.2.Phase B: Response Support
- 2.3. Phase C: Evaluation
- 2.4.Impact of the practice and factors facilitating it
- 2.5. Transferability of practice
- 2.6. Evaluation of the impact of practice
- 2.7.Cost assessment
- 2.8.User participation
- 2.9. Additional Feedback

## 3. Good practice 2 – Housing First (HF) Residences

- 3.1. Phase A: Preparation and Involvement
- 3.2. Phase B: Response Support
- 3.3. Phase C: Evaluation
- 3.4.Impact of the practice and factors facilitating it
- 3.5. Transferability of practice
- 3.6. Evaluation of the impact of practice
- 3.7.Cost assessment
- 3.8.User participation
- 3.9. Additional Feedback

#### 4. Conclusion

## 5. Bibliography

#### 1. Introduction

GIRA - Grupo de Intervenção e Reabilitação Ativa (Active Intervention and Rehabilitation Group), is a Portuguese IPSS (Social Solidarity Private Institution) that works with people with severe mental illness and psychosocial disability. Its main mission is to "promote the rehabilitation and social inclusion of people with mental illness, investing in their potential and proximity to caregivers and the community."

To achieve this goal, GIRA has a multidisciplinary team that bases its intervention on the community model of intervention, where the participation and self-determination of the person with mental illness is evidenced, being this an active element in their rehabilitation process. Fundamental concepts such as *empowerment and* recovery are valued, *and* the main work instrument is the Individual Rehabilitation Plan (PIR). This is elaborated with the user in a holistic perspective and centred on their potentialities developing life goals and delimiting strategies to overcome the difficulties, aiming at a life fulfilled with objectives and with meaning.

GIRA has six Social Responses, specifically, two Fóruns Sócio-Ocupacionais (Socio-Ocupational Day Centers) (1 in Lisbon and 1 in Almada) and four Residences (3 protected and 1 autonomous). In addition, it also has two Autonomy Support Residences (RSA), one located in Benfica and the other in Cacilhas, and three Housing Responses of Customized Housing, Based on the *Housing First* Model. These last two responses constitute two good practices of GIRA, with collaborative strategies, and will be the subject of study throughout this report.

# 2. Good Practice 1 - Autonomy Support Residences (RSA)

The residencies to support autonomy are the first experience of the organization, in these moulds, being an innovation within the organization. They arose from the need to respond to several requests from families and professionals over the years, due to the scarcity of residential responses to mental illness and the lack of vacancies in existing responses, particularly in the district of Lisbon.

It should be noted that the territories of Benfica and Cacilhas, where these answers are located, have a high population density, given their urban nature; being two townships of the metropolitan area of Lisbon, with a strong incidence of mental pathologies.

Given the existing constraints for the creation of new responses, and supported by a solid network of partnerships, both in the townships of Benfica and in the municipality of Almada, GIRA created these 2 residences for people with mental illness, with a greater degree of autonomy, but in need of support for their clinical stability and social integration. It was possible to cover new

territories, such as the municipality of Almada where there was no housing response of this type; and new public, who do not need 24-hour supervision, but who need daily support, although reduced.

The Autonomy Support Residence (RSA) located in Benfica has the capacity to support 7 people and was created in March 2020; and the RSA located in Cacilhas has a capacity of 5 people, having been inaugurated in October 2021.

This typology of residences constitutes integrated responses in the community, having as its main objective the training of psychosocial skills, within the scope of psychosocial rehabilitation programs, with a view to a progressive independence, of the people with mental illness who reside there.

#### 2.1. Phase A: Preparation and Involvement

The referral process for this response is done directly to the institution, and can be done by the patient, by family / friends or by other entities of the social or health sector.

After the first contact, information is provided on the type of services provided and the operation of the response; what are the admission criteria; existence or not of vacancy and rules of management of the waiting list. Information is requested, namely personal data and clinical and social information to carry out the initial assessment of requirements. Admission criteria are having a mental illness, age over 18 years, being in the phase of clinical stabilization, adhering to medication and being linked to the external consultation of a psychiatric unit.

After indicating the admissibility or not for the response, it is integrated into the waiting list and if there is a vacancy, the evaluation process is immediately initiated, proceeding to a social and psychological evaluation and visit to the facilities.

After collecting all the information and, if the person maintains interest, the team evaluates all the elements collected and decides if the user meets the necessary criteria for integration in the response. If these criteria are met, the user signs the service contract and integrates the answer.

It is elaborated with the user the reception program where the main needs and services to be provided in the reception are defined. There is a trial period of 3 months, and at the end there is an evaluation of the integration of the user, carried out by all the technicians of the response and by the user himself. If the evaluation is positive, either on the part of the user or on the part of the institution, the integration of the user in the response is confirmed. From there, evaluations of the user are made periodically.

After the evaluation of the trial period, the PIR (Individual Rehabilitation Program) and the Step-by-Step are elaborated, building a rehabilitation plan, with specific objectives and what strategies to achieve them.

During the day the user must have an occupational program, which may be the integration in an occupational response (Fórum Sócio-Occupacional (Socio-Occupational Day Center) or another program of activities chosen by him); vocational training or labour market.

There is no maximum length of stay in the housing response, since each case is evaluated individually and considering the capacities and needs of each user.

#### 2.2. Phase B: Response Support

Each RSA has a multidisciplinary team, consisting of Social Worker or Psychologist, who provides support during the day (monday through friday); a monitor, with training in the area of Social Sciences and Humanities, who supports from 17h-21h (rotationally), every day of the year; and an auxiliary worker who supports 4 hours a week. The team also has the technical coordination of a psychosocial rehabilitation technician. In the absence of the team and, whenever necessary, the technicians are available by phone.

Integration in this response presupposes that the user has a degree of autonomy and rehabilitative potential, according to the level of supervision.

This response provides shared accommodation and includes food, hygiene and general housing expenses.

In these units are also provided the following services:

- a) support and supervision in self-care and activities of daily living;
- b) supervision and management of medication and supervision of the trip to psychiatry and physical health consultations;
- c) psychosocial support;
- d) articulation and support to the family and/or support network;
- e) promotion of an occupational, training or employment activity;
- f) conviviality and leisure activities.

In the intervention, individualized teaching of competencies is promoted, in areas such as: hygiene and personal care; activities of daily and domestic living (cooking meals, shopping and home economics; routines, including cleaning and organizing space; and treatment of clothing); financial management; and medication management.

There are also activities to train personal, social and professional skills, with the objective of promoting the autonomy of the person, as well as their insertion in the community, privileging the proximity to the various community resources.

Departures and contacts with families and friends are also promoted, in order to maintain and strengthen family ties and strengthen their social support network.

#### 2.3. Phase C: Evaluation

The evaluation of these residences has been continuous and carried out by the project team, through monitoring instruments (records, evaluation grids and balances), Scales (applied before and after an intervention time) and questionnaires of satisfaction user/families/partners.

It has relied on the consulting, supervision and monitoring of LIGMH (*Lisbon Institute of Global Mental Health*<sup>50</sup>).

In addition to the evaluation of the person and the strategies to be adopted to achieve their objectives, it has been sought to evaluate the relevance, adequacy, effectiveness and impact of these responses, as well as their intervention methodology.

## 2.4. Impact of the practice and factors facilitating it

Since 2020, the RSA of GIRA has had 17 integrated users (11 users in Benfica and 6 in Almada).

From the characterization of the users who have already integrated the answer, they have an average age of 50 years, mostly male (58.82%) and with the 12 years of schooling completed. Most of them were referred by family members and have been attending, on average, the answer for about a year and a half. The most frequent diagnosis is schizophrenia, and most clients are monitored by a family doctor and psychiatrist.

In terms of family and financial situation, we found that a large number of users have family support and most benefited from the economic support of the Social Benefits for Inclusion (PSI) and its complement. We emphasize that, although they have some state financial support, through pensions and social benefits, this is often not enough to fully cover their expenses.

Some of the integrated clients were referred to other, more appropriate answers, or were integrated into their family throughout their rehabilitation process.

Throughout these years of work, there were several factors that contributed to the success of the response:

a) Family support - most of the users integrated in these residences have solid family networks, which are involved in the rehabilitation process of the user, constituting essential supports for the success of the intervention. In addition, the fact that these families have also established a

<sup>&</sup>lt;sup>50</sup> Institute whose main objectives are to generate innovative knowledge, develop training activities and provide technical collaboration to governments and non-governmental organizations in the areas of mental health and social determinants; mental illness and chronic illness; mental health policies and services; mental health and human rights. From the development of epidemiological research and services, offering training to individuals and institutions, providing technical assistance to countries and non-governmental organizations and promoting or joining international collaborative networks for research, training and technical cooperation (Lisbon Institute of Global Mental Health, 2022).

- good relationship with the institution and with the technical team, represents a protective factor for the proper functioning of the response and for the rehabilitation of the user.
- b) Existence of financial support most of the resident users benefit from financial support (e.g. Social Benefits for Inclusion, Complements to the Social Benefits for Inclusion, training or employment grants, support from Social Services), allowing the monthly payment of the response, as well as some financial autonomy for personal expenses.
- c) Receptivity of the community and partners GIRA users count on the receptivity and support of several partners and the community in which they are inserted, having the opportunity to enjoy a wide variety of resources at the training, occupational and leisure level. This openness contributes to an integration and active participation in the community, stimulating skills and promoting the autonomy and well-being of users.

Despite the facilitating factors mentioned, there were also some challenges and difficulties, at the level of:

- a) Interpersonal relationships and conflict management between users;
- b) Stabilization of routines, with difficulties in the fulfilment and maintenance of routines and commitments, especially at the level of your occupational or training program.
- c) Stigma, sometimes, there is a need to promote psychosocial skills and reflection in users, regarding risk and/or inappropriate behaviours that can facilitate, maintain and/or increase the stigma associated with these populations. On the other hand, the need to intervene in the community, demystifying and sensitizing them, with a view to understanding some behaviours.
- d) The environment lived in these units is a promoter of well-being and tranquillity, which inhibits residents from risking their autonomy for a more independent life in an individual residence and is also aggravated by the economic needs of the majority.

## 2.5. Transferability of practice

In terms of the transferability of practice to different contexts, we can identify the following essential factors:

- Identification and knowledge of territorial needs for the creation of a new response, it is essential to know the territory and identify its needs and potentialities. This will allow the development of appropriate and useful local responses for the community, aiming at promoting the quality of life of vulnerable subjects.
- Credibility and solidity of the institution being an institution with responses already implemented in the community and with the work recognized, either by partner entities or by

the community itself, facilitates the creation and development of new projects, such as this one. The experience of the institution and its collaborators is joined by the existence of partnerships already established and the trust of community elements and structures and local mental health services.

- Partnerships – having a solid partner network is an essential factor for the success of a new response, providing support at various levels (e.g. provision of spaces, financial support, etc.), filling gaps and enhancing the dissemination of the work done and its quality.

## 2.6. Evaluation of the impact of practice

Throughout the years of operation of the RSA, continuous evaluations were carried out to all users, exploring issues such as: quality of life, physical and psychological well-being, satisfaction with the answer, evaluation of the period of experience, among others. In this sense, in addition to the daily behavioural observation and the integration of the knowledge of the various elements of the multidisciplinary team, several quantitative and qualitative instruments were used, such as:

- World Health Organization Quality of Life (WHOQOL-Bref);
- World Health Organization Disability Assessment Schedule (WHODAS 2.0);
- Scale of Independent Living Skills;
- Satisfaction Questionnaires of the User / Family / Partner.

With these evaluations, it was possible to verify the impact of the practice on the lives of users, and the following results were found:

- General improvement in the physical, psychological, environment and social relations domains (WHOQOL-Bref);
- Significant improvements in the domains of cognition, interpersonal relationships, self-care and mobility (WHODAS 2.0);
- Improvements in medication management, activities of daily living and travel abroad (Trial Period Assessment);
- Satisfaction with the facilities, activities performed, services provided and reception process (Evaluation of the Trial Period);
- Greater participation, collaboration in household chores and responsibility of users. Satisfaction at the level of psychic stability and sense of well-being of your family member (Family Satisfaction Questionnaire);
- High satisfaction with the residences, as well as with the work developed in them and recognition of the response as a resource available in the community for people with this vulnerability (Partner Satisfaction Questionnaire).

#### 2.7. Cost assessment

The residences that support the autonomy do not have their own financing, so the residents pay with a fixed monthly amount (on average  $20 \notin$  / day - Benfica and  $15 \notin$  / day - Almada), which allows the payment of the expenses of the apartment (rent, food, hygiene, house expenses) and the technical support appropriate to their needs.

The properties of the residences are located in urban areas, with access to services and public transport. In Almada the municipality ceded an apartment, in a model filed with a symbolic income, which decreased the costs of the response, being an example of collaborative partnership. In Benfica, the urban lease regime was used, making the response more expensive.

To equip the apartments with furniture and appliances, we counted on donations from other associations and companies, within the scope of social responsibility.

For the sustainability of these residences, GIRA has also sought the monetization of its own resources, namely: human and material resources; making applications for funding and requests for donations. It is noteworthy to state that the financial support of the National Institute for Rehabilitation (INR, I.P.), in the 2 years since the start of the project – 2020 and 2021, through the Participa project<sup>51</sup>, which allowed to strengthen the team and consequently the therapeutic offer to users.

Residents pay a fixed monthly fee that covers accommodation, food and technical support. It should be noted that it is sought that all users have access to the responses, regardless of their economic resources, resorting to support from Local Social Action, when this is necessary.

Since 2020 it has been possible to maintain these responses in a sustainable way and at an affordable price for most people, taking into account the social supports available. We cannot fail to mention that it is the very one that bears most of the costs of the response, and that being chronic and disabling diseases, it could be a service with a contribution from the state. Despite this assumption, only in this way was it possible to support these 17 people over these 3 years. However, we can also analyze under the prism of personal responsibility, being people who have in view an autonomization, seeking to follow paths to an independent life, this can be a training for an adequate management of the available resources, with a view to success in the future, being this one of the great difficulties in these pathologies.

Finally, taking into account that the prices applicable to long-term care units and teams (Ordinance No. 272/2022, of November 10<sup>th</sup>), with regard to residences, are between 39.80€ / day - 53.10€ / day, according to the type of response and that in autonomous residences with the minimum

<sup>&</sup>lt;sup>51</sup> Project, aimed at the RSA, supported by INR, I.P.

of supervision is 13.42€ / month, It seems to us that these can be a cost-effective model and suitable for more autonomous people, but who need a response with technical and transitory support for a more independent life.

#### 2.8. User participation

As mentioned earlier, the fundamental objective of the RSA response is to promote the psychosocial rehabilitation of its users, intervening in order to develop their maximum autonomy and independence. To this end, all users are encouraged to take an active role in this process, having the freedom to delimit their personal life goals and to make the necessary choices to achieve them. The technical team has a constant support role, without ever restricting the individual freedoms and rights of each user.

The users also have an active role in all the dynamics of the residence, participating in the different scales of household chores, suggestion of menus, weekend programs, among others, which are decided in a weekly group meeting.

#### 2.9. Additional Feedback

Finally, it is also important to mention the work developed by GIRA, in the scope of social networks and communication, noting a constant effort to involve the community, sharing records of the activities carried out by users, as well as information on mental health, promoting awareness of these themes and combating the stigma associated with them.

In addition, the institution's participation in campaigns and events in the community (e.g. fairs, conferences, lectures, etc.) is also highlighted, with the aim of disseminating the work developed by the team and enhancing literacy related to mental health and psychosocial rehabilitation. Users have an active role in all this work, participating in each step and using their voice and experience to make known the reality and difficulties of this population, as well as their abilities and dreams for the future.

# 3. Good Practice 2 - Housing First (HF) Residences

This project was based on the American model *Housing First*, which has been operating in the United States for more than 20 years. It is a response created to integrate homeless people into housing, accompanied by technicians available 24 hours, who accompany them in learning how to manage a house, with a view to their social and community integration (CML, 2021).

It began in Lisbon, in 2009, through the association AEIPS - Association for the Study and Psychosocial Integration. Being that currently there are several municipalities and associations that

work with this project and hundreds of houses scattered throughout the metropolitan area of Lisbon (CML, 2021).

This practice develops an interventional program for populations of individuals living in homeless conditions, with the first objective of integrating the beneficiaries into their own housing. The premise "home as a human right" presupposes the possibility of dignified living conditions, before any rehabilitative psychosocial intervention, allowing users to develop feelings of security and stability that will leverage their social and community inclusion, as well as the success of other objectives specific to each case.

It begins to be applied in Portugal in 2017, with the Resolution of Ministers no. 107/2017, of July 25, within the scope of the National Strategy for the Integration of Homeless People (ENIPSSA), which establishes the intervention and monitoring models for the period 2017-2023.

GIRA embarked on this project in July 2021, with three *Housing First* model apartments for homeless people with experience in mental illness. Although GIRA acts only at the local level, this model is implemented by several entities at the national level.

## 3.1. Phase A: Preparation and Involvement

Before the beginning of this project, GIRA and NPISA (Homeless Planning and Intervention Centers, coordinated by the Almada City Council - CMA) were already partners for a long time, there was no intervention from a technical point of view with people in homelessness, there were only street teams. It began by constituting a street technical team that only georeferenced these people. From this is born the project PIIPSSA (Integrated Project of Intervention with People in Homelessness in Almada), having as partner entities: Centro Social Paroquial N.<sup>a</sup> Sr.<sup>a</sup> da Conceição da Costa da Caparica (local parish social center), NPISA (more generalist social intervention), GIRA and Vale de Acór<sup>52</sup> (more specialized intervention - area of mental illness and consumption and dependence of alcohol and drugs, respectively).

Within this project there were 3 responses: case management (street and shelter), daytime space to be built and *housing first* responses for homeless people, being the responsibility of GIRA, 3 houses for homeless people with mental illness. The application for Portugal 2020 was made – it is a Partnership Agreement between Portugal and the European Commission, aiming to guide the use of the European Structural and Investment Funds during the period from 2014 to 2020. This

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<sup>&</sup>lt;sup>52</sup> IPSS focused on dependency recovery.

agreement aimed to boost economic, social and territorial growth in Portugal, following the principles of Smart, Sustainable and Inclusive Growth outlined in the Europe 2020 Strategy.

This application was approved, and in September 2020 the project started in its practice and in July 2021 the CMA project coordination approved the launch of the housing responses. After the elaboration of the internal regulations, the process of enabling the houses to be inhabited within the proposed budget began. After the selection of the users, and their evaluation, the houses were assigned to the users, based on their not only mental situation, but also their physical health comorbidities.

#### 3.2. Phase B: Response Support

This practice implements housing policies and basic social policies (access to housing), which touches all areas of life, since the person integrates the house and throughout the process of intervention/monitoring (e.g. health, employment, training, vocational rehabilitation, etc.).

When the person integrates the project there is no obligation to be framed in the treatment process or state of stability of the pathological picture. This is justified by the basic premise of the project, in which the house is the starting point for the rest of the intervention. Ultimately, the stage of the journey in which health care is implemented will depend on the cases, however, when these are implemented are not limited to any type of care, integrating health care of general or specific medicine, such as mental health or other medical specialty.

The technician makes visits once or twice a week, and is contactable 24 hours, these visits can be made at home or in another place of choice or need of the users. Depending on the needs, it is normal for the technician to make a weekly visit, a phone call and a trip to any place of need. The duration of the visits is about 1h/1h30. There is a weekly meeting with the three *housing first* users to share experiences, empower and strengthen ties to support each other.

#### 3.3. Phase C: Evaluation

Every semester a qualitative evaluation report is prepared by the technician, and no quantitative or external evaluation has yet been made, since the project is very recent. However, periodically the PII (Individual Intervention Plan) is prepared with the users, together with a diagnostic evaluation form.

In the evaluation process of the selected users, the following instruments are applied:

- Housing First *Response Application Form*;
- Social Diagnostic Assessment and Mental State Assessment Form (internal instruments of GIRA;
- List of Activities of Daily Living;

- Suicidal Intent Scale and Beck Suicidal Ideation Scale.

#### 3.4. Impact of the practice and factors facilitating it

The adaptation process is not easy, for reasons of previous life history, but feelings such as: capacity, security, privacy and control over one's own life and routines significantly increase and improve the perceived quality of life (a situation that contrasts to a large extent with shelter or street situations).

There are, however, visible improvements:

- In the general quality of life, higher level of perceived safety, higher level of perceived comfort, stabilization of the psychic state, hope, increased psychoeducation that leads to knowing how to deal better with the symptomatology, etc.
- Expansion of the relational and support network of the beneficiaries (e.g. the case of a user who on the day he entered the house resumed contact with the family).
- In personal independence, less emotional and affective dependence on third parties.
- In sociability and social behaviours, fewer individualistic behaviours and social isolation.

Undoubtedly one of the factors that most facilitated the implementation of this practice was the partnership with the CMA that created the project, the availability and will of the NPISA and the financing, both of the Portugal 2020 partnership, as well as the POR Lisboa 2020<sup>53</sup>, both ruling between 2014 and 2020.

#### 3.5. Transferability of practice

The most important for the successful transferability of this practice is the knowledge and subscription in political terms, national and local, of the basic premises of the project (having a house is a right of all; and the non-obligation of a series of criteria, usually of exclusion (e.g. being in treatment).

The existence of a social diagnosis of needs, which substantiates the relevance; carrying out a cost analysis; and taking into account the support available for funding is also key to its successful implementation.

Finally, having a consolidated and available network of partners are essential factors to implement the responses and enhance the intervention, in a perspective of interinstitutional articulation.

<sup>&</sup>lt;sup>53</sup> Project aimed to reinforce regional competitiveness, significantly intensifying investment in innovation, research and development and the diversification and strengthening of small and medium-sized companies, with a view to their internationalization and participation in growth and innovation processes.

## 3.6. Evaluation of the impact of practice

From the beginning, the general trends that we have observed in users, with regard to the impact of integration in these responses, we can highlight:

- Activities of daily living general improvement, with some difficulties in the sense of activities they have never done (e.g. shopping).
- Formative or occupational process general improvement, began to have an occupation during the day and objectives of training and employment.
- Relations with family members improvement and rapprochement and stable maintenance of the relationship with family members.
- Relationships with peers general improvement, with stability, tranquility and control over your life relationships improve automatically, are even forming new friendships.
- Integration in the community maintenance and general improvement, this process also did not start from scratch, that is, when the integration in the house was made, the process began with the users still on the street and in the shelter. They have built autonomy in the use of resources and integration in the community.
- Money management/Economic situation not applicable to all cases but has been successful in those that do occur.
- Leisure general improvement, integrate into various leisure activities alone or with GIRA and other institutions.

At the national level, the implementation of this practice by other entities (e.g. AEIPS - Association for the Study and Psychosocial Integration), since 2009, has been demonstrating an undeniable success: the beneficiaries report an improvement in their mental health and quality of life, associated, for example, with the ability to perform activities that they previously did not perceive as possible, since after integration into the program, they find in the technical team the support and support they need, either in all the household charges, or in the monitoring or articulation with services or institutions, which consequently promotes access to them (Andrade, 2021); significant reduction in the use of hospitalizations and emergency services (Andrade, 2021; Smith, 2014); clearly positive results in terms of effectiveness and cost-benefit efficiency (Duarte, Costa & Ornelas, 2018).

#### 3.7. Cost assessment

In terms of costs the houses were ceded for the project by the Almada City Council, which also carried out the necessary works, to build studio apartments out of social buildings' old meeting rooms.

For the equipment of the 3 houses, a grant from the project was counted on, within the scope of the application to Portugal 2020, having been possible the acquisition and installation of furniture, appliances and all the articles necessary for the establishment of a house. The constitution of the technical team was also financed by funds from Portugal 2020.

In this project there is a contribution from the beneficiary user, sharing with 20% to 30% of their per capita income (net income, minus the expenses with chronic medication and travel).

In order to enable the implementation of the PIIPSSA project and its activities, namely the establishment of the *Housing First apartments*, *the* funding resulting from the Portugal 2020 partnership, established between Portugal and the European Commission, was preponderant.

With the end of the project, in July 2023 a protocol was signed between the Almada City Council, GIRA and the other partner associations of the project, for the continuity of the intervention, allowing to ensure the technical team, communications and travel.

## 3.8. User participation

All beneficiaries participated, to some extent, in the process of implementing the practice, in activities such as: purchase and assembly of furniture and equipment, cleaning and other activities developed in the primary stages of the building of houses for housing.

They also actively participate in the entire rehabilitation process, through the PII (Individual Intervention Plan) outlining life goals and strategies to achieve them,

Finally, it is up to each user to manage their own home, taking control of their life independently, with the technical team as a rear guard and support.

## 3.9. Additional Feedback

The team believes that this model and these responses are appropriate for this type of population, and it is very important to expand them in the future.

# 4. Conclusion

In the two recent projects, presented as good practices of GIRA, we highlight the collaborative practices with other entities for the implementation and continuation of the same; and the response to needs not covered, either by public services or by the social sector, due to lack or scarce responses, legislative limitations and/or lack of funding.

Considering the incidence of mental health problems in Portugal, the access of people with mental illness to differentiating answers and services that promote independent living and their quality of life is urgent.

The importance of civil society having an active role and promoter of change and the relevance of establishing functional partnerships and cooperation for the promotion of responses in the area of mental health, including the public and social sectors, always with a view to the effective social integration of people with mental illness, is highlighted.

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# III. C- SOLARIS' GOOD PRACTICES

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# Good practice 1: pathways to independent supported housing: "The keys of the house"

Introduction

After the deinstitutionalization processes started in almost all countries, residential services (from psychiatric residences to halfway houses to personal accommodation) have been widely implemented in the field of mental health and several studies on good practices related to housing in mental health are being spread internationally.

What is emerging from these studies is the difficulty in identifying services that have all the characteristics necessary to be proposed as models. An English study of over one hundred cases of "supported housing", confirms, after the systematic review of quantitative studies carried out to identify evidence on psychosocial outcomes for people residing in supported housing services, the difficulty since the variation in the terminology and characteristics of each service makes it impossible to compare the models adopted. There is heterogeneity in the literature on supported housing, in terms of research quality, experimental design, population, types of services and outcomes evaluated.

In the paragraph dedicated to *Housing and housing-related support (supported accommodation)* of another document, the "Position Paper on community-based mental health services", drawn up by five European experts and financed by the Health Programme, is reiterated the difficulty in presenting good practices in the field of supported (assisted) housing.

Although the cases analyzed are conflicting, the documents agree in considering the effectiveness of supported housing linked to deinstitutionalization processes, as it reduces people's hospitalization rates and improves the appropriate use of local services, even if it is not possible to reach models that can be reproposed in different contexts.

The studies at the national and international level have the aim of presenting models of good practices of "supported accommodation" services which concern the different types of accommodation (from psychiatric residences to independent homes) and which can be transferred (mutatis mutandis) to other contexts.

Many of the difficulties of the services analyzed through these studies are linked to the role of the network of public bodies in organizing the paths towards autonomy. Difficulties which, however, can be overcome when the direction of these paths is assumed by the families, who operate in a network with the territorial entities.

This is the case of the service offered by the Solaris Association in the "Paths towards a supported apartment: The keys to the house", a specific housing solution in collaboration with the social and health services of the 2nd Municipality of Rome, with which it has collaborated since its founding.

The Solaris Association is made up of family members and volunteers and, through a bottom-up planning that starts from those directly involved and involves all the stakeholders in the area, it has developed an exportable service model which has proven to be valid over the years and which falls within the parameters to be assumed as transferable Good Practice.

#### 1.1 Scope and objectives of the practice

Solaris was founded with the primary intention of supporting the recovery paths of persons with mental health problems leaving protected residences or inadequate family situations, facilitating the possibility of living independently in owned or rented accommodations. Solaris supports them in finding a housing solution appropriate to their needs, in managing everyday life and in and in the socialisation paths. At the same time, it supports those who intend to remain in their family of origin. In any case, the intent is to encourage de-institutionalisation paths that allow people to feel "at home", in their own and lasting living spaces.

#### 1.2 Stakeholders and Area

The target group of this practice is represented by adults with mental health problems residing in the II Municipality and in charge of the Mental Health Center ASL ROMA 1 District 2, coinciding with the Rome 2 Municipality. There are 30 people supported per year.

The service is carried out in the II Municipality of Rome Capital, characterized by the presence of cutting-edge interventions in comparison with the treatment of mental distress. In particular, the supported housing experience, now active since 2002, has assumed great importance and sees the collaboration between Solaris odv and the UOC II of the Mental Health Department of the ASL Roma1, specifically the "via Sabrata" therapeutic community and the CSM (Mental Health Centre) of via Sabrata and via Boemondo, in agreement with the II Municipality. The II Municipality financially supported the autonomous living project from which the good practice in question originated with a direct contribution until 2017, and subsequently through a call for tenders.

The II Municipality of Rome Capital is a complex territory with a high population density and a population between 150.000 and 170.000 people (2021 Registry data) where very different socioeconomic situations coexist and the following territorial public mental health services are present: two Mental Health Centers (CSM), a therapeutic community (Residential Therapeutic Rehabilitation Facility for extensive community treatments), three Day Care Centers, a Residential Socio-Rehabilitation Facility, a Flat Group, two addiction services, two life services for the protection of mental health and rehabilitation of childhood, a primary care outpatients clinic for the protection of young people aged between 14-25 with mental distress.

#### 1.3 Description of the practice

Every year, Solaris supports the paths of 30 people with mental health problems, in the charge of the CSM and residents of the II Municipality. The users involved in the supported independent living paths are followed for the clinical part by the CSM, and supported by Solaris odv in regaining control of their daily life and in their socialisation paths, according to these types of phases:

## Phase A: User referral, project launch, definition of personalised care paths;

*User referral*: the referral takes place by the CSM to the social worker coordinating the project, to the municipal contact person for the project and to the manager of the UOC Mental Health ASL ROMA1 District 2.

*Project launch*: an initial cognitive meeting is held between the CSM operator who promoted the referral, the user, the family if present, and the Solaris social worker, the project coordinator. The user

will be informed of the existence of the service offered and the related resources, emphasising the fundamental role of their being an active part in defining his or her needs and the implementation of support interventions.

Personalised path: In a subsequent meeting between the user and the reference operator, the personalised treatment path is defined using the "Recovery star" tool. By means of a score to be attributed to a series of spheres of activity concerning different areas of life (e.g. self-care, work, social networks, etc.) the user will be asked to create, with the help of the operator, a chart able to provide an overall vision regarding the areas of his/her life and their functioning, on which the care path and the personalised educational project will be based and constructed.

The personalised project allows to outline the interventions to be implemented, the short-, mediumand long-term objectives and the consequent follow-up timeframe.

The monthly schedule of hours for home care is calibrated according to the needs of the people and their previous experiences.

#### Phase B: Placement in the accommodation

To people who go to live in independent accommodation, the Association's team offers "light" and "flexible" assistance, with an average of 12 hours of support per week, appropriate to people's needs.

The presence of Solaris operators in the accommodation varies depending on the period and according to needs: for example in the early days, when people are most in need, the hours of assistance can become 18-20, but in certain periods of greater stability they can also be reduced to 4 hours per week. However, phone contacts with the Association's operators are constantly ensured.

#### Basic services include:

- a. Support in the normal carrying out of daily activities, in particular personal care, domestic help and home care, carrying out bureaucratic procedures, shopping and personal purchases.
- b. Activities to combat isolation by supporting users in resocialisation activities and in strengthening relationships with primary and secondary networks, in particular by encouraging them and accompanying them to participate in social and leisure activities offered by the territory
- c. Telephone support from operators which constitutes a very important element of reassurance and balance for users
- d. Support and accompaniment towards the creation of new cohousing projects. Among those who are about to start a path to independent living and for whom the possibility of cohousing is hypothesized, some cornerstones for the initial path should be kept in mind:

nypoinesized, some cornersiones for the initial pain should be kept in mind:
☐ direct involvement of users in the choice of home, roommates and furniture
$\square$ search for flats as close as possible to the user's reference neighbourhood
□ support for paperwork and contracts, and facilitation of relationships between the people with whom the experience will be shared

The professional figures foreseen for supported independent living are: the educator, the social worker, the rehabilitation technician and the social and health worker. The different professionals may alternate in support depending on the user's problems and needs.

The definition of individual paths is confronted with the subjectivity of the users, with the richness and diversity of the needs expressed by users, and must take into account the continuous changes that the user goes through.

In order to operate within this complex framework, a 'flexible assistance model' has been implemented, and widely tested by the most innovative trends in international psychiatry.

The Mental Health Centre does not directly intervene in the management of support for daily living activities. But it constitutes the point of reference for managing the clinical dimension of individual users.

Solaris always involves family members in the activities it carries out, and, depending on their availability, they can become important subjects of the socialization activities, which are also open to volunteers and operators.

#### Phase C: Evaluation

This practice is a winning case of collaboration between families and the territorial socio-health system.

Once the personalised plan has been developed and the placement of the person in the accommodation has started, the periodic verification of the progress of the person's activities and conditions begins. The verification is carried out by a monitoring team made up of Solaris, a social worker from the Mental Health Centre and, when necessary, other professional figures, and a contact person from the Municipality.

Different survey tools are used (Recovery Star, quarterly reports from the monitoring team, monthly reports from the project coordinator on the objectives achieved and the activities carried out, a satisfaction questionnaire and focus groups) to assess the person's progress and any difficulties, allowing the results obtained to be quantified also in the comparison between the different paths, highlighting the critical and successful elements of both the individual paths and the intervention as a whole.

Together with the user, the team evaluates the conditions on which to intervene or not and the methods of intervention necessary to overcome the highlighted deficits and enhance his path to autonomy. If problems arise in the social sphere, Solaris addresses them; if the problems concern the health sector, the contact person at the Mental Health Centre takes charge of them.

The Solaris social worker, coordinator of the project, draws up a monthly report on the objectives achieved and the activities carried out. This report will be used by the coordinator in the monitoring group meetings.

#### 1.4 Practice impact indicator

According to a 2010 research (Maone, Domiziani 2010) from 2003 to 2010, 11 people were supported by Solaris in their independent living experiences. Of these, over 70% still live in independent accommodations today. Of the others, some preferred to be placed in flat groups with a greater number of people and with 12-hour daily care, while, still others returned to their family of origin.

Of the people who live in independent accommodation, only 30% have resorted to hospitalization in psychiatric residences for short periods.

Several factors facilitated the implementation of the practice:

- a. From the beginning the practice was born from a bottom-up approach of the families' planning, who obtained the support of the therapeutic community and the local Mental Health Centre and managed to involve the local authorities as well. The network created by families with local public social and health services is essential in ensuring support for the person who goes to live in an independent home.
- b. Another positive factor is the constant awareness of the neighbourhood in which the person is going to live, awareness favoured by the availability of the neighbourhood which has always shown itself receptive to coexistence with people with mental health problems. Solaris regularly promotes activities involving the neighbourhood in squares or parks, either autonomously or in cooperation with other public or private territorial entities (Universities, shops, etc.).
- c. The person's economic independence facilitates, their placement in an independent accommodation, but in the case of users who only have a disability pension, which is insufficient for renting an accommodation, the Mental Health Centre intervenes with a housing subsidy, which can reach the sum of  $\epsilon$ 700 per month and which originates in a fund that the Municipality of Rome has allocated to mental health care.

#### 1.5 Obstacles to the implementation of the practice

The Municipality does not have public housing for this specific target group, so people who do not have the necessary economic strength to go and live in a flat must depend on the support of the Mental Health Centre, which activates municipal funds. To date, the necessary funds have been sufficient, but if they are not enough for all requests, this could be an obstacle.

It is precisely the non-existence of other options that made families create this practice aimed at the independence of people with significant mental health problems.

## 1.6 Transferability of the practice

Essential factors for the transferability of these paths towards independent housing are:

- the existence of a strong association of family members and users who build a network with local social and health services and which guarantees the protection of the paths that people take towards independence;
- the association's support to the family of origin;

- the realisation of activities that also involve the neighbourhood;
- -the involvement of these people also through other projects that facilitate their socialisation or training.
- 1.7 Evaluation of the impact of the practice

Research carried out on Solaris interventions to support people with mental disorders by placing them in independent accommodations, has shown that 70% of these people still live in independent accommodations today.

The success of this service has been ensured by a financially support of the social and health services. People in the neighbourhood with mental problems and their families turn to Solaris to start an independent life path.

In Solaris' twenty years of experience in this field, the Association has not faced any problems with the neighbourhood.

1.8 Cost assessment.

Solaris receives  $\in$ 75,000 annually to provide social assistance to 30 people in their flats ( $\in$  2.500 annually each). A notable difference compared to the costs of hospitalization in Psychiatric Residences or other residential communities which can range from  $\in$ 100 per day up to  $\in$  200 (in high-intensity care residences). The cost-effectiveness of Solaris is evident, even if one counts the possible  $\in$  700 per month of the housing allowance.

1.9 User participation

The personalised projects were created with the participation of interested people.

The service users have been involved in the decision-making process that led to the implementation of the practice through constant participation, even during the COVID period, ensured by the various WhatsApp groups.

1.10 Additional information

From the numerous public events open to the public that Solaris regularly organizes and/or manages (meetings, conferences, seminars), emerge positive feedback which is often reported in the documents that Solaris publishes (the PausaCaffé magazine, conference proceedings, etc.).

Solaris supports people by using not only the resources of the Municipality of Rome but also other additional resources from other projects, involving them in socialising or training activities and guaranteeing them in this way not only home care.

All published documents can be downloaded from the Solaris website (https://www.solarisodv.it/)

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## Good practice 2: "families challenging the stigma of mental illness"

Solaris' information and editorial strategy falls within the setting of lifelong learning, when learning times and spaces expand until encompassing every area of life and all the person's time, and places the information at the centre of a non-formal learning system, open to the community of families and the territory.

## 2.1 Scope and objectives of this practice

This good practice is aimed at combating the prejudices and stigma that accompany mental illness. The Solaris community contributes to the dissemination and development of awareness and a different perception of mental illness in people, through an information and editorial strategy aimed at placing users and families in the foreground and spreading information and information throughout the territory through various channels, created first-hand by those interested in mental health issues.

This activity has a double value: in addition to being a resource for the Solaris community and the authors, who find a space through which they can express their thoughts, sensations and emotions, it is also a way of communicating, involving and raising awareness in the territory, facilitating the dissemination of information that contributes to the elimination of prejudices by the protagonists. Furthermore, the publications help create a link between society and the most marginalised people, thus promoting their inclusion.

#### 2.2 Stakeholders and Area:

The Stakeholders are: a) people with mental health problems, who, through the writing and public presentation of publications, acquire a leading role; b) caregivers and volunteers, who participate in the development and dissemination of information products, also acquiring a leading role; c) the institutions and the general public, whether social and health workers or private citizens, who are involved through the public events that Solaris regularly organises, or through the internet and social networks.

Solaris' information and editorial strategy is carried out at a local level and its direct contacts are local, but its range of action and impact, through the internet and social networks, becomes national as all documents and information are readable and downloadable by all interested parties. Recently the activities have had an international diffusion participating in the Erasmus+ programme.

- 2.3 Description of the practice. Solaris information represents a key objective of the Association and is achieved through an editorial strategy that involves those directly concerned and adherents and was founded in 2014. It is implemented through:
- A) The establishment of thematic groups involving members and adherents, organized on the specific topics that mark the life of the Association. The groups, of variable participation and duration, meet via WhatsApp or in attendance to share elements for reflection and for concerted elaboration of products to be disseminated;

- B) The organization of and active participation in public events, through which are disseminated the activities carried out by Solaris and the presentation of publications and literary products created by users, bringing to light the extraordinary abilities of those who are socially marginalised;
- C) The involvement of a network of external actors (experts, social and health workers, citizens and artists) who contribute to feeding the information process through the elaboration and exchange of documents, works and original products;
- D) The editorial production of the six-monthly PausaCaffè magazine and books and brochures of various kinds:
- the magazine "PausaCaffé" is an information medium on topics of general interest and specific experiences of Solaris members or people interested in mental health issues. Initially, it was published annually, since 2020 it has become a six-monthly publication. Sixty copies of the magazine are reproduced and distributed throughout the area during all events organized by Solaris or in which the Association participates;
- the books and brochures, an expression of the various projects that Solaris undertakes and the creativity of its members and adherents. Some are specifically related to the institutional role of the Association and deal with issues of a socio-health nature (paths towards supported housing, conference proceedings), while others reflect the cultural production of the members of the Association in its various dimensions (poems, cuisine, environment, etc.).

The editorial products are free, they can be downloaded from the Association's website (https://www.solarisodv.it/) and, during public events and meetings with the territory, they are often distributed with the voluntary contributions of the participants.

- E) The site offers comprehensive information on Solaris' activities, services, projects, editorial production and events, and provides access to the archive of older products and activities. Technically, it is maintained by an experienced volunteer. It is updated every three months by an experienced family member who is responsible for the editorial work of Solaris. The Facebook page is maintained by an experienced family member, the president of the association, with the support of an IT expert volunteer.
- 2.4 Impact of the practice and factors facilitating it. The participation in publications of people with mental health problems as authors and their interventions in public events as readers of poems and texts produces very positive effects both in themselves and in their families, giving them denied visibility and the role of protagonists.

The participation of social and health workers, in support of the information activities of family members, makes the fight against prejudice a concrete shared objective.

The increased participation of people outside the association (artists, other citizens) in the information activities highlights and reinforces the positive impact of Solaris' information activities.

Several factors facilitated the implementation of the practice:

- -New technology and social media facilitate the possibility of communication within the Solaris community and connections with the outside world;
- -The Association has an autonomous office, that allows to organize small events, meetings and workshop activities and is well connected to all local services;
- The office is self-financed and does not depend on external financing;
- The presence of professional skills among family members and volunteers (graphic designers, journalists, computer experts, etc.) made it possible to realise the editorial activities;
- The presence of a network of relationships with associations and institutional structures has enabled the collection, dissemination of information and implementation of activities to promote Solaris.
- 2.5 Obstacles to the implementation of the practice.

Editorial production must be widely shared with members and adherents to gather their consensus, which slows down the processing and dissemination times of documents. This requires the activation of strong coordination, recognized by the members, which makes it possible to find the right balance to quickly achieve the set objectives.

We are currently in the process of identifying privileged interlocutors in the media, as representatives of the Association, to ensure regular dissemination of information and create greater loyalty among the recipients of the information.

- 2.6 Transferability of the practice. There are several factors necessary for the transferability of the practice:
- -The activation of social networks, which enable active participation and broaden the impact of the Association's activities, also in other areas of distress;
- -Institutional participation, providing a visible role for information activities;
- The autonomy of the office relative to funding, which can only be temporary;
- -The experience and professionalism of users, family members and operators, and the enhancement of the expertise that is acquired through the various activities.
- 2.7 Evaluation of the impact of the practice

Various qualitative and quantitative indicators demonstrate the significant increase in the positive impact of the activities that Solaris organizes to break down the prejudices that marginalize families and users of the various areas of the Association's information and editorial service:

- the mailing list of information recipients has doubled in the last five years (n...);
- the participants in the various WhatsApp groups have also doubled (info 30 coffee break 56, etc..);
- the magazine, initially annual, became six-monthly three years ago;

- in the last two years, two volumes have been reprinted;
- the participation in editorial products of new authors external to Solaris has increased;
- -the request for participation of Solaris members (people with mental and family problems) in external events has doubled over the last four years.

The increase in people's participation in publications and events is reinforcing and enhancing the role of families and the most marginalised people.

- 2.8 Cost assessment. The professionals and some experts (users or not) who work on the texts of the publications are paid through the projects, and the printing of most of the different documents is also financed through projects. The utilisation of the voluntary work of numerous experts constitutes an important increase in the economic potential (and savings) in Solaris' activities.
- 2.9 User participation. The service users are involved in the decision-making process that led to the implementation of the practice through constant participation in editorial activities, also ensured during the COVID-period, by the various WhatsApp working groups, by connections on the Zoom platform and in person.
- 2.10 Additional information. All published documents can be downloaded from the Solaris website (https://www.solarisodv.it/)

2.11 Contact person

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## All. 1)

#### **OCSE – EVALUATION CRITERIA**

The OECD DAC Network on Development Evaluation (EvalNet) has defined six evaluation criteria – relevance, coherence, effectiveness, efficiency, impact and sustainability – and two principles for their use.



#### **RELEVANCE -** IS THE INTERVENTION DOING THE RIGHT THINGS?

The extent to which the intervention objectives and design respond to beneficiaries, global, country, and partner/institution needs, policies, and priorities, and continue to do so if circumstances change.

Note: "Respond to" means that the objectives and design of the intervention are sensitive to the economic, environmental, equity, social, political economy, and capacity conditions in which it takes place. "Partner/institution" includes government (national, regional, local), civil society organisations, private entities and international bodies involved in funding, implementing and/or overseeing the intervention. Relevance assessment involves looking at differences and trade-offs between different priorities or needs. It requires analysing any changes in the context to assess the extent to which the intervention can be (or has been) adapted to remain relevant.

\* Beneficiaries is defined as, "the individuals, groups, or organisations, whether targeted or not, that benefit directly or indirectly, from the development intervention." Other terms, such as rights holders or affected people, may also be used.

#### **COHERENCE - HOW WELL DOES THE INTERVENTION FIT?**

The compatibility of the intervention with other interventions in a country, sector or institution.

Note: The extent to which other interventions (particularly policies) support or undermine the intervention, and vice versa. Includes internal coherence and external coherence: Internal coherence addresses the synergies and interlinkages between the intervention and other interventions carried out by the same institution/government, as well as the consistency of the intervention with the relevant international norms and standards to which that institution/government adheres. External coherence considers the consistency of the intervention with other actors' interventions in the same context. This includes complementarity, harmonisation and co-ordination with others, and the extent to which the intervention is adding value while avoiding duplication of effort.

#### **EFFECTIVENESS - IS THE INTERVENTION ACHIEVING ITS OBJECTIVES?**

The extent to which the intervention achieved, or is expected to achieve, its objectives, and its results, including any differential results across groups.

**Note:** Analysis of effectiveness involves taking account of the relative importance of the objectives or results.

#### **EFFICIENCY - HOW WELL ARE RESOURCES BEING USED?**

The extent to which the intervention delivers, or is likely to deliver, results in an economic and timely way.

**Note:** "Economic" is the conversion of inputs (funds, expertise, natural resources, time, etc.) into outputs, outcomes and impacts, in the most cost-effective way possible, as compared to feasible alternatives in the context. "Timely" delivery is within the intended timeframe, or a timeframe reasonably adjusted to the demands of the evolving context. This may include assessing operational efficiency (how well the intervention was managed).

## **IMPACT - WHAT DIFFERENCE DOES THE INTERVENTION MAKE?**

The extent to which the intervention has generated or is expected to generate significant positive or negative, intended or unintended, higher-level effects.

**Note:** Impact addresses the ultimate significance and potentially transformative effects of the intervention. It seeks to identify social, environmental and economic effects of the intervention that are longer term or broader in scope than those already captured under the effectiveness criterion. Beyond the immediate results, this criterion seeks to capture the indirect, secondary and potential consequences of the intervention. It does so by examining the holistic and enduring changes in systems or norms, and potential effects on people's well-being, human rights, gender equality, and the environment.

#### **SUSTAINABILITY - WILL THE BENEFITS LAST?**

The extent to which the net benefits of the intervention continue, or are likely to continue.

**Note:** Includes an examination of the financial, economic, social, environmental, and institutional capacities of the systems needed to sustain net benefits over time. Involves analyses of resilience, risks and potential trade-offs. Depending on the timing of the evaluation, this may involve analysing the actual flow of net benefits or estimating the likelihood of net benefits continuing over the medium and long-term.

#### EXPLANATION OF THE GOOD PRACTICES IN MENTAL HEALTH

https://rm.coe.int/inf-2020-5-form-for-collection-of-examples-of-good-practices-in-mental/16809efd00

## **ADDENDUM**

Name of the practice:

Address of the place where the practice is carried out:

- 1. **In which areas is the practice implemented** (healthcare, employment, housing, training/education, social policies...)?
- 2. If the practice is linked to healthcare, at which stage of the health care path is it implemented (general health care, admission, follow up...)?
- 3. What is the aim of the practice?
- 4. **Does the practice address a specific situation** (crisis situation, follow-up to hospitalisation, homelessness...)?
- 5. **Individuals concerned** (persons with specific mental health needs, specific groups such as adolescents/young adults, elderly persons, health care professionals...)?
- 6. Scope or area of the practice: national/regional/local?
- 7. **Detailed description of the practice and how it is carried out,** including length and frequency, if applicable.
- 8. **Indicator of the impact of the practice**(feedback from service users/family members/service providers/health professionals; decrease of recourse to involuntary measures...), including any available information on the medium- or long-term impact of the practice.
- b) Additional useful information (to be submitted only if available)
- 9. Factors which have facilitated the implementation of the practice.
- 10. Information on the barriers to the implementation of the practice, if any.
- 11. Which **other options** were available?
- 12. Which factors are considered essential for **transferability of the practice** into a different setting?
- 13. Formal assessment of the impact of the practice (external or self-evaluation)
- 14. **Cost evaluation** (costs/saving analysis)
- 15. How were the **service users involved** in the decision-making process leading to the implementation of the practice?

- 16. Any additional feedback from stakeholders (service users, family members, health professionals, social workers etc.)
- 17. Any **additional statistical information** relating to the short-, medium- or long-term impact of the practice
- 18. Information on any **on-line or other resources** (tool kits, guides, reports...)
- 19. **Detail of a contact person** who could be contacted to request further information, if needed.