AIDA

Advancing Integration for a Dignified Ageing

MINISTERO DEL LAVORO
E DELLE POLITICHE SOCIALI

AIDA Project

Social and health care guidelines for frail disabled and elderly people

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introduction

INTRODUCTION TO THE GUIDELINES

Like all complex systems the social and health care system needs criteria and directions to guide and support its services in the most efficient and effective way possible. The AIDA project has developed these social and health care guidelines with the aim of providing "recommendations" to systematically support organisational structures and critical policy decisions regarding the elderly and non-self-sufficient people in general, by providing service professionals and policy makers with directions for setting up and managing the most appropriate care methods.

With this in mind it is necessary to point out that health and social services cater to people defined as being psychologically or physically "frail", for whom the care system must also include assistance for environmental, family and economic conditions. If care interventions are not adequately supported by actions that facilitate maintenance/rehabilitation in the living environment, their effectiveness is limited and the problem of social exclusion remains. In short, health care must go hand in hand with social cohesion and the struggle against inequality.

The merging of health and social services is therefore "imperative" to be able to organise universal and integrated responses, just as institutional governance is needed to direct the basic processes that see to the health care and quality of life of frail people. In this sense then, the Guidelines take into consideration, by means of specific recommendations, both organisational structures and care processes, providing information that can be explored in further detail in the attached materials.

1. spatial dimension

Spatial dimension is a key factor affecting both the usability of services and their systemic organisation. It is thus proposed that appropriate scales of size, population and mobility be identified. Italian national and regional legislation identifies a territory with 100,000 - 150,000 inhabitants as an ideally-sized land area for social and health care services, adjusting the size (downwards) according to the hilly and mountainous areas present in the District. Law 328/2000 (a framework law for the integrated system of interventions and social services), suggests that the "social" fields coincide with those of the health aspect, giving rise to what has been created in various Italian regions - the Social and Health Care District - a facility that unites the social and health care functions.

The spatial overlapping of the two management areas also leads to a different result, that of combined management by the municipalities in a given area to provide social services (Article 8 Law 320/2000). All of this, in addition to allowing for a more systemic organisation of the social aspects (also in terms of affordability), makes uniform and integrated access to the network of services possible through the District health organisation.

The Social and Health Care District is capable of implementing the best possible level of integration between not only local services, but also between these and hospitals compared to other organisational models. The integration provided by the Social and Health Care District can be summed up in four strategic areas:

1. integration of inputs from the local health authorities (ASL) and municipalities;
2. professional integration of social and health care personnel and territorial jurisdictions;
3. organisational integration of the community and hospitals;
4. Integration of public services and accredited entities with particular reference to third sector and volunteer associations, so as to create horizontal subsidiarity.

spatial

2. access to the social and health care system

An important consideration regarding access to the social and health care system in terms of simplifying it for citizens and system unity is that of identifying a “single access point” that can also be geographically convenient. The Single Access Point (or, more simply SAP) therefore provides an organisational modality for universal and uniform access to social and health care services, particularly aimed at those individuals who have complex health needs that require both health care services and social protection measures. The SAP becomes the first service available to the citizen for providing information and starting the access and continuity of care process.

The SAP may be made up of smaller “sub-access points” throughout the territory that are connected electronically to the facilities that initiate access and continuity of care operations. The SAP’s main functions include access, admissions, collecting reports, guidance, handling requests, direct activation of services in response to simple needs and the start of the access and continuity of care process and integration with the network of primary care and hospital care services.

In order to accomplish these tasks, the SAP performs several functions, some of the main ones include:

1. providing information and guidance;
2. recording access;
3. evaluating needs;
4. opening individual files to collect data essential to determining the situation of the person requesting social and health care services, including for epidemiological purposes;
5. referring cases to the appropriate services so that they may initiate the access and continuity of care process.

3. multi-dimensional needs assessment

Complex needs require evaluations that take several aspects into consideration: the psychological and physical situation of the person with particular reference to his/her functional independence, life and relationships, financial resources, and all of this requires a multi-dimensional approach. The multi-dimensional assessment (MDA) may thus be defined as a global and dynamic interdisciplinary process designed to identify and describe the nature and extent of a person's physical, mental, functional and relational/environmental problems.
The primary purpose of the multi-dimensional assessment is to measure a person's state of health, degree of autonomy and self-sufficiency, the personal and family resources on which they depend and the economic conditions that may affect them and (if the individual is not self-sufficient), his/her living conditions. The MDA leads to the formulation of the Individualised Support Plan (ISP). The use of assessment tools and scales is important for making a thorough analysis of the functional capabilities and needs of the elderly/disabled individual for the MDA, which includes the biological, cognitive, social and functional dimensions.

The multi-dimensional assessment is carried out by a mixed team made up of health and social care service providers that generally includes a medical practitioner who specialises in "frailty", a general medical practitioner, a nurse, a rehabilitation therapist, and the social worker in charge of the person being assessed. Italian regions use different scales to obtain objective assessments that take into account the different profiles of the person so that appropriate care decisions are taken. Those most tested and that are also most inspired by international guidelines are:

- the SVAMA (*Scheda per la Valutazione Multidimensionale dell'Adulto e Anziano, Questionnaire for the Multidimensional Assessment of Adults and the Elderly)*, which also has a variant for disabled individuals (SVAMDI), analyses all aspects of the life of the person requiring access and continuity of care. It consists of four sections that assess health variables, the degree of self-sufficiency, social relations and financial situation, providing operators with a complete and general framework for assessing the "quality of life" of the individual requesting social and health care;
- the AGED Plus (*Assessment of Geriatric Disability*) questionnaire taken from the French system, AGIR, provides for an assessment, similar to SVAMA, but in a more simplified and faster manner by analysing 27 functions and providing information about the medical, nursing and caregiver services required each day in addition to the individual's pathology/self-sufficiency level;
- the RUG (*Resource Utilisation Groups*) system is a classification system that was created in English hospitals to provide a "medical and social profile" of the elderly, for the purpose of determining the care plan;
- Core set/ICF Protocols: (*International Classification of Functioning, Disability and Health*) are a list of codes compiled from a selection of the complete international classification of Functioning, Disability and Health, including perspectives such as individual, relational and environmental factors that best describe the life of a person in relation to his/her health/autonomy. It is a system used in Italy mainly for disability; however, various experiments are in place that involve not only the use of social and health services, but also inclusion in vocational training and work.

The instruments/scales mentioned are those most widely used, however, some regions have adopted instruments that have more local value but are equally good for evaluating health, autonomy, and personal and societal resources.

4. individualised support plan

The Individualized Support Plan (or, more simply ISP), is a systemic work programme delivered by the multi-professional team developed from the information contained in the multi-dimensional assessment that identifies attainable objectives based on the evaluation of the needs of the person requesting care, and the social and health services needed to reach them, offering an on-going and ex-post evaluation of the results, adjusting - if necessary - services provided. The ISP provides an evaluation of the appropriateness of the planned services and their effectiveness, along with the costs.

For reasons which include shared responsibility, the ISP should be signed by the user (according to his/her psychological and physical condition) and, by the family (caregivers), together with the person in charge of the plan (also known as the case manager). The ISP is reviewed during its implementation according to changes of the situation being handled, but above all there should be an evaluation at the end of the intervention in order to verify its effectiveness and cost. In many regional systems (e.g. for the "Regional Funds for Non Self-Sufficiency"), the ISP has become the instrument for defining the "covenant of care" with the family in situations involving services and monetary payments to assist non self-sufficient individuals.

Finally, the Individualized Support Plan is an excellent tool for measuring the appropriateness and effectiveness of interventions, including the manner in which the continuity of care is implemented for the person being given access and continuity of care and thus the degree of strategic systemic organisation of social and health care activities and their efficiency under the multi-disciplinary profile.

5. continuity of care

All stakeholders involved with complex social and health care needs require a model of care whose goal is the "access and continuity of care".
The access and continuity of care leads to social and health care approaches in settings (home, residential and semi-residential) that do not "add up" but rather are integrated and recomposed into a unified framework of responses to the need that has persisted over time and include the curing or stabilisation of health and inclusion problems. The services should/may be provided by different professionals, who have different professional qualifications or work in different fields (general practitioners, specialists, hospital admissions, individual/family social support personnel). A decisive role is that of the case manager.

The continuity of care should be monitored, especially when there is a transition between various settings. A particularly important time in the continuity of care for frail people is that of "protected" discharges from the hospital to a home or residential facility. Especially upon returning home, the continuity of treatments must be ensured so that the benefits gained are not lost. The continuity of care must become a systemic form of "approach" used by operators in dealing with frail individuals, so that the person is not abandoned to the segmentation of services.

Continuity of care in the medical, nursing and social support spheres should be especially ensured for:

- people who come from an acute care setting and, if discharged from the hospital without continuity of care being properly secured, are at high risk of a relapse and, consequentially, re-hospitalization;
- people in a chronic state (even if stabilised), who live at home or in facilities with minimal health care activity), who are easily disposed to relapse episodes if not properly cared for.

Integrated management of the patient requires the implementation of organisational models at both the managerial and professional level that act to ensure the continuity of care with a uniform and coordinated use of resources. Fundamental for the construction of such a system is the widespread use of Diagnostic and Therapeutic Care Pathways (Percorsi Diagnostico Terapeutici Assistenziali, PDTA) and Integrated Care Protocols (Protocolli integrati di cura, PIC), meaning the creation of integrated service plans, that may also result from special guidelines to deal with chronic diseases or complex clinical problems where social intervention is also needed. These are useful tools for describing the shared objectives and actions of the various components involved in the care (operating both in the territory and in hospitals), aimed at delineating the most practicable pathway in terms of appropriateness, and favouring a process approach over individual care episodes. The protocols are also important for allocating available resources in the most appropriate and targeted manner.

Implementation of the PDTA requires that clinical and organisational indicators, volumes of activity, and expenditure ceilings be defined. In Italy, PDTA and PIC are dedicated to chronic illness and form part of the contractual responsibilities of General Practitioners.

6. home care: home care and integrated home care

The continuity of care calls for different levels of care to be provided to the patient and to the caregivers themselves. Individualised care plans need to consider the possibility of building a service network around the person that favours the patient's stay at home. Only when there is an "obvious" lack of an adequate support network, including that of help from people outside the family (caregivers and volunteers), should the choice fall to forms of residential care for individuals who cannot be receive integrated home care (IHC) or forms of domiciliary hospitalisation (DH).

There are different degrees of home care that may provide forms of personal care/protection through the use of a personal aide for the non-self-sufficient person, who also performs family-home related tasks (cleaning, preparing food and feeding, grocery shopping, assisting with personal hygiene, doing the laundry, etc.), arranged for by the family, even by hiring people for this purpose (a family assistant better known as a "caretaker" that has basic training in caring for the elderly/disabled). Municipalities and their home care assistance service associations (Servizio domiciliare per anziani, SAD) can provide limited home care, also through the use of partner agencies or other entities. This kind of assistance does not replace nursing care or rehabilitation, but is aimed at the prevention, maintenance and recovery of the residual potential of the person to enable them to remain in their own homes and in their own relationship contexts.

Integrated Home Care (IHC) is a form of integrated home treatment combining health care services (nursing, rehabilitation and medical) and domestic and protection services to support the person in the event of chonic disease relapses or hospital discharges. IHC is defined as the whole spectrum of coordinated health care services integrated with social care provided at home and aimed at meeting the needs of the elderly, the disabled and patients with chronic degenerative diseases, who are partially or totally non self-sufficient and require on-going assistance during care and rehabilitation.

IHC is supported by the Individualized Support Plan through the multi-disciplinary management of the patient with the coordination of general practitioners, medical specialists, rehabilitation therapists, nursing staff, caretakers, and social and health care workers. The IHC service can be requested by the general practitioner, the head of the hospital ward upon discharge, the social worker or by the family of the non-self-sufficient individual.

Several different forms of IHC are related to the intensity of health care and personal care assistance (medium and high level), which, according to the severity of the person's condition, must provide a daily presence and, sometimes, multiple treatment courses in a single day. Special intensive IHC including treatments provided to patients with cancer and end of life care must follow high-intensity care protocols.

It should be emphasized that in cases of particularly long-term chronic illness, IHC should be supplemented by family care, especially for protection and personal assistance support.

7. residential and semi-residential care

When it is not possible to care for the non-self-sufficient person at home, other forms of care at special residences may be necessary. Residential care is divided into two types: that of day care or semi-residential care and that of continuous or residential care.

Day care should provide personal care assistance and rehabilitation (if necessary), entertainment, socialisation and, also meal services. It is designed for elderly and disabled people at high risk of losing their autonomy or those who are already non self-sufficient and may also suffer from some form of dementia, especially those affected by Alzheimer's. It is an intermediate service between home care and residential care that is usually conducted in a "Day Care Centre" and provides rehabilitation for disabled persons, acting to prevent the worsening of the situation and providing support to the family and especially to caregivers. It is as yet a still little-used measure, though it is an extremely useful way to prevent completely severing ties with the family and the living environment.

Residential Care is also aimed at people with limited autonomy, including those with psychological problems who require round the clock assistance, especially when family support is not available. It is full-time care that offers similar services to those provided in day care, though more comprehensive and intensive, especially in terms of care. The most common structures in Italy are RCFs (Residential Care Facilities), which offer a medium level of health care services (medical, nursing and rehabilitation), complemented by a high level of protection and hospitality. There are other types of residential social and health care facilities in various Italian regions with different levels of health care services, and there are also facilities "dedicated" to people with dementia that make use of forms of "prosthetic" care to facilitate recovery and delay the loss of autonomy.

There are also smaller facilities called "substitute family care" that mainly provide social assistance in the form of accommodations known as community housing and/or protective shelters. These do not have medical personnel but only staff to help protect people and govern the house, taking advantage of the health services offered by the District and the general practitioner.

Access to residential and semi-residential facilities should be preceded by a multi-dimensional assessment and the preparation of an Individualised Support Plan for the elderly and disabled to take with them the facilities.

Other forms of residential care include intermediate facilities sometimes called "community hospitals" or by other names. These facilities may also be found in hospitals and provide post-acute stage care for persons with multiple chronic illnesses in relapse phases; these are citizens who, after the acute phase of the illness, are clinically unstable and therefore require further clinical observation, continuity of care, nursing and rehabilitation. Access to the intermediate facilities is usually made after a hospital stay to ensure continuity of care.

8. case manager

The case manager is professional identified from within the multi-disciplinary team during the MDA and the preparation of the ISP, whose role is to work with the General Practitioner to guide and coordinate services on the basis of what is outlined in the Individualised Support Plan. The case manager can manage one or more cases in his/her role as "director" of the social and health care interventions that are carried out for the person being cared for at a determined place or time.

The case manager may come from either the social or health care professions, depending on the prevalent nature of the services. The regulations regarding social and health care services in Italy do not qualifications for this role. Experience undertaken to date usually sees this role assumed by nurses and the General Practitioner.

Case management is configured as a process to schedule, coordinate and evaluate the types of facilities and services required to meet the needs of the patient, handling communications between the different stakeholders in the access and continuity of care and assessing/managing the available resources (human and financial) in order to foster and implement the most appropriate services for the person. Thus, Case Management is also a mechanism for improving the effectiveness and efficiency of social and health care services, mainly through the coordination of resources that can be used to solve the health care and personal care issues relating to the non-self-sufficient person.

The case manager follows the progress of the case from the initial access and continuity of care through the monitoring and completion of the ISP and therefore is:

- The contact person between the user and the caregiver (family members and/or professionals);
- The coordinator of professional resources;
- The person responsible for monitoring and evaluating the ISP;
- The person in charge of managing the financial resources allocated for the case;
- The person responsible for ensuring the quality of the service.

9 • role of the family and the caregiver

The family plays an important role for the non-self-sufficient person especially if it is able to provide constant care, but also as a point of reference if the care is left to other people. A caregiver (or carer) is an unpaid family member who helps an individual (family member, friend, acquaintance, etc.) who is not able to independently perform daily living activities due to age, illness or disability.

A proper continuity of social and health care pathway needs to consider the fundamental role of the family of the person being cared for, as being central to the process of access and continuity of care that defines the care pathway. Evaluating the ability of the family network to provide care will help determine the most appropriate pathways for the actual situation and the choice of different levels of intensity of the care pathway.

The role of caregivers must be recognised and value placed on it as a resource that provides for the continuity of care system.

family

10. professionals

Several professional roles are necessary for the social and health care process to work, both for the treatment component (nurses, rehabilitation therapists, general practitioners and other medical specialists, etc.), as well as for the care/education aspects which involve social workers, educators, activity organisers, and family caregivers. Integration of the various professions involved is essential for preparation of the ISP in such a way as to ensure a comprehensive response to the problems of the non-self-sufficient person and secure the proper treatment/care conditions that offer the most effective manner to deal with needs which, owing to their complex nature, require a multi-professional response.

This response must be the result of a coordinated structuring of services that originate from different professional approaches and unite in the process of solving the needs of the non-self-sufficient person or individual with severe disabilities. Professional integration is a motivational opportunity for each operator to make the most of his/her specific contribution.

TRAINING

Training is an instrument for optimising human resources and organisational change. Training means making changes in terms of awareness (knowledge), capacity (skills), and attitudes (know-how). It requires a careful estimate of professional needs.

Training should be performed in the broader context of the service policy and coherent integration with other professional disciplines. Training, by its very nature, has the ability to make qualitative changes in the results of services and overcome organisational breakdowns. It can facilitate managerial and professional restructuring and can - more broadly - take the form of a strategy to increase the effectiveness of services.

The training process should be understood in three ways:

- cross training: relating to processes that apply integrated policies (health and social, social education, etc.) and information about the services available in the area;
- technical training: relating to particular skills and leadership roles held within the organisation, so that these may become more efficient and effective in the context of continuity of care pathways;
- inter-professional training: represented by the exchange of ideas between different operators and professionals based on their experiences.

For social and health care service operators, long-term learning or, "lifelong learning" is the best support method for professional development and the exchange of experiences.

VOLUNTEERS

Volunteer work is the most important outcome of social solidarity. It is not a substitute for professional staff when providing care and assistance, but rather it acts to support such services and the family by providing valid support activities, especially in the most complex and serious cases. Its role is critical to care processes, ensuring a presence for the non-self-sufficient person, as well as offering moments of relief to the family and caregivers. The role of the volunteer should be directed and defined by those in charge of the person.

11. integrated management of financial resources

The overall access and continuity of care for the person, along with the ability to implement multi-disciplinary interventions that respond to multiple illness situations, oriented towards the biological-psychological-social model requires a basic social and health care service budget, which may be the result of various financial contributions from different public and private sectors (health, social, costs of care shared by the user, etc.). This ensures that the funds are pooled, on the basis of the Individualized Support Plan, in a virtual resources container that provides the greatest possible rationalisation and control over expenditures. The budget also allows the applicant access to faster and better coordinated services, where the objective is the integration of services and thus the continuity of care.

INFORMATION SYSTEM

The Information System (IS) is the basis for planning and managing a system of services. A reliable and constantly updated information flow provides the ability to analyse access and continuity of care processes and patient management. It also provides the tools necessary to implement models of care based on cooperation between the stakeholders and integrated management of care and support pathways. The availability of epidemiological data also allows the targeted allocation of resources according to expenditure sustainability, eliminating inappropriate actions.

The New Health Information System (Nuovo Sistema Informativo Sanitario, NSIS) and the Social Information System (SINA for non-self-sufficiency, and, SIMBA for child care and poverty) are important reference tools for measuring the quality, efficiency and appropriateness of services to be offered.
The NSIS can provide information regarding support given to people in different regions and in different care settings. The residential and semi-residential care information system (FAR) is part of the NSIS. It monitors the services provided in residential and semi-residential care for non-self-sufficient people. The home care information system (SIAD) monitors social and health care interventions provided in the home.

The classification of non-self-sufficient people has been seen to by the Ministry of Labour and Social Policies together with the regions in the Non Self-Sufficiency Information System (Sistema Informativo Non Autosufficienza, SINA)[1] which includes a psychological and physical profile of non-self-sufficient individuals, and their level of autonomy and family support, in order to assess the social and health care services to provide.

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[1] The necessary information can be found in an individual file that takes into account a minimum set of data relating to: bodily structure function (impairments), activity (limitations) and participation (restrictions). The assessment of non-self-sufficiency is made by analysing five areas: function (autonomy in daily activities), cognition, behaviour, health (presence of (chronic) illnesses), and social arrangement (formal and informal assistance). The combination of the autonomy/health areas generates a psychological and physical profile of the non-self-sufficient person and the consequent burden of care.

inform

12. monitoring and evaluation of outcomes

Monitoring of the progress of activities, expenditures and the achievement of the expected results (i.e. an overall assessment of the effects, and verification of their correlation and consistency with the goals and the impact of the intervention for the improvement of the person's condition), is fundamental to the success of the interventions. The monitoring and evaluation of outcomes process should be understood on two levels:

1. monitoring and evaluation of the results of the individual pathway of the person being cared for, which allows on-going evaluations to be made that can react to changes in health status and life context and include a possible reassessment of the intervention and budget;
2. monitoring and evaluation of the results regarding the more general social and health care policies activated, which, as we said in the previous recommendation, should be based on a secure, reliable and up-to-date flow of information that allows services to be measured in terms of their appropriateness and effectiveness. This will also provide data on interventions and facilitate the judicious use of human and financial resources to eliminate waste, as well as the possible reallocation of resources towards more appropriate services or processes that are able to adapt to the new emerging needs.

The monitoring and evaluation of outcomes should always be performed using reference standards (indicators) that have been formulated and accepted in advance. The monitoring and evaluation system is able to provide an overview of the organization of the services adopted (especially for integrated services) in terms of their effectiveness, efficiency, cost, perceived quality and appropriateness.

partnership

The AIDA project is coordinated by Liguria Region.

The partnership involves public entities and national and international NGOs actively dealing with the integration of social and health care services for older persons:

- Veneto Region
- INRCA
- Anziani e non solo società cooperativa
- ENEA APS
- Eurocarers

The project implementation is also supported by the following associated partners:

- Italian Ministry of Labour and Welfare Policies
- EDE – European Association for Directors and Providers of Long-Term Care Services for the Elderly
- ELISAN – European Local Inclusion and Social Action Network
- UNCCAS – Union Nationale Centres communaux ou intercommunaux d’action sociale
- ENSA – European Network of Social Authorities

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