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Guidelines for creation of the Local Action Plan for palliative care development

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Introduction

The project We care, implemented by regional partners BELhospice Serbia, Civic Alliance Montenegro, Sue Ryder Albania supported by BCSDN Macedonia and funded by SIDA envisioned support local governments in the project region to enable them guidelines for creation of the Local Action Plans for palliative care improvement.

Population in the project region is ageing and an increasing number of people are living longer. In all three countries (Serbia, Albania and Montenegro) palliative care is in early stage of development and the population aging rapidly increasing as well as the incidence rates of life-threatening illnesses (such as cancer, neurological and cardiovascular diseases), the improvement of infrastructure, services and network capacity building is seen as a developmental priority. The system needs to change to meet the growing demand for palliative care.

Local governments should take adequate actions to improve palliative care services and prepare for these trends to meet the needs of vulnerable citizens. An action plan is needed to provide a structured approach to inclusive and collaborative strategic planning and to improve the priority areas work in practice.

Guidelines for creation of the Action Plan will enable support to the local governments in design of future palliative care services to meet increasing demands and support stakeholders to focus their priorities, planning and resourcing for change.

Guidelines describe palliative care concept, the role of the local government in developing palliative care services and provide adequate processes that should take place during development process of mapping of existing needs ad potentials, engagement of the stakeholders.

Brief overview of the stage of palliative care development and needs for service improvement will be presented. Policies that include local government role to develop palliative care services for vulnerable population will be examined.

This will affect better access to palliative care and implementation of fundamental right to dignity of its citizens and affect improved accountable governments that meet the needs of its citizens.

What is palliative care?

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems. Palliative care is the prevention and relief of suffering of any kind – physical, psychological, social, or spiritual – experienced by adults and children living with life-limiting health problems. It promotes dignity, quality of life and adjustment to progressive illnesses, using best available evidence. Palliative care for children represents a special field in relation to adult palliative care. Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease. All people, irrespective of income, disease type, or age, should have access to a nationally determined set of basic health services, including palliative care. Financial and social protection systems need to take into account the human right to palliative care for poor and marginalized population groups.

Palliative care may often be seen simply as giving painkilling medicines. The rationale for palliative care certainly includes the need for relief from pain and other distressing symptoms, but it goes further to include efforts to enhance the quality of life, and even influence the course of illness in a positive way. Life is affirmed and dying is regarded as a normal process, with care integrating physical, psychological, social, cultural and spiritual aspects. Patients are helped to live as actively as possible until death, and a support system offers help to the family to cope both during the patient's illness and during bereavement.

Palliative care is not intended to hasten or postpone death, but uses ethical principles, shared decision-making and advanced care planning to identify patients' priorities and goals for their care at the end of life. A team approach is used and many kinds of health and social care providers, as well as volunteers, can be involved. It is important that palliative care should not be considered as something that only hospitals can do. It can be provided in any health-care setting and also in patients' homes and can be successfully implemented even if resources are limited. Palliative care services should, therefore, at a minimum: n identify patients who could benefit from palliative care; n assess and reassess patients for physical, emotional, social and spiritual distress and (re)assess family members for emotional, social, or spiritual distress; n relieve pain and other distressing physical symptoms; n address spiritual, psychological and social needs; n clarify the patient's values and determine culturally appropriate goals of care. The essential practices in primary palliative care can be classified into four categories, namely: physical care, psychological/emotional/spiritual care, care planning and coordination, and communication

Who needs palliative care?

Palliative care is required for patients with a wide range of life-limiting health problems. The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Patients with many other conditions may require palliative care, including kidney failure, chronic liver disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis. Children may have a high incidence of congenital anomalies and genetic conditions and mortality is highest in the neonatal period. Each year an estimated 20 million people are in need of palliative care in the last year of their life, with many more requiringpalliative care prior to the last year of their life. Of these people in need, 78% live in low- and middle-income countries. For children, 98% of those needing palliative care live in low- and middle-income countries

Pain is one of the most frequent and serious symptoms experienced by patients in need of palliative care. Psychosocial support is another common need in palliative care. Patients with life-threatening or terminal illness and their caregivers go through great stress, and health professionals treating them need to be adequately trained or prepared to help them manage their stress.

Community based palliative care

Community-based palliative care is defined as palliative care delivered outside of the hospital setting. There is an increased interest in healthcare organizations providing palliative care in the community to meet the needs of patients with serious illness who are neither hospitalized nor ready or eligible for hospice. Community-based palliative care has opened the door for better access to specially trained teams of doctors, nurses, and other specialists who work together with the patient's medical team in order to add an extra layer of support for patients and their families and improve their quality of life. Availability of services in the community settings can include office practices, medical clinics, long-term care facilities, and patients' homes. Several studies show that community palliative care reduces hospital and emergency department visits, lowers acute care costs, and improves care continuity, quality of life, and survival outcomes.

Community palliative care should anticipate:

- Proactive identification of high-risk beneficiaries
- Comprehensive assessment of symptoms and stressors impacting quality-of-life
- Expert management of symptoms and stressors by an interdisciplinary care team1
- Patient and caregiver education and support, explaining what to expect, clarifying goals and values, supporting shared decision-making and advance care planning
- Develop services to meet personal care needs
- Care plan coordination across all providers and community services

- Ongoing support of patients and families including telehealth with 24/7 access
- Accountability for patient experience, quality of care, and cost
- Innovative payment mechanisms that fully support care delivery

Increasing exposure to palliative care in the community may help diminish stigma and reshape attitudes toward palliative care.

These community volunteer workers integrate into communities and gain the trust of patients and their families by providing culturally sensitive care that respects patients' values regarding dying and death and thereby increases the willingness of communities to use palliative care services.

Needs for improvement of Palliative care

The wide-ranging impact of the pandemic on health and social services including delays to surgeries and consultations, an increase in long-term conditions and changes to how health and social care is delivered – is anticipated to result in a sustained increase in demand for palliative care, exceeding previous forecasts.

In all project countries, patients currently do not have enough choice or control over decisions taken about their care. Too many people with life-limiting illnesses – as well as those approaching death – are spending long periods of time in hospital unnecessarily, without the option of an alternative care setting. Hospital admissions have been rising to unsustainable levels and risk overwhelming parts of the health system during the Covid-19 pandemic.

The shortage of palliative care expertise, especially in social care and community settings is further compromising patients' experience.

Palliative care development[1] has been considered across five broad domains: education and training of health care providers in palliative care, access to opioid medications, professional and public attitudes toward palliative care, integration of palliative care into national health care systems, and palliative care research.

There are several factors at the level of health care service delivery and clinical practice that are also necessary for widespread palliative care development. These include educating and training of a broad range of mainstream health care providers, alternative and traditional healers, community volunteers, and providers of psychosocial and spiritual support. Culturally sensitive communication strategies are also needed to facilitate discussions about death and dying and advanced care planning. Efforts should also be made to facilitate the provision of end-of-life care at home, in hospice, and in hospital.

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[1] https://ascopubs.org/doi/full/10.1200/JGO.2017.010090

Public awareness of and acceptance of the need for palliative care is essential for the use and uptake of palliative care services.

Both policymakers and health care providers have a role in ensuring that the general public is educated about palliative care, and that palliative care services are available and implemented in a timely fashion. Such education will help to combat the stigma of life-limiting and life-threatening conditions. Strategic interventions are needed at the levels of policy, clinical care, and the community to promote development in all domains of palliative care.

Palliative care and legislation in Serbia

Even though in terms of legislation, the Republic of Serbia recognises the need to organise the service of palliative care for this extremely vulnerable category of patients, and also the rights of patients to get palliative care if they suffer from incurable diseases this right is not easily applied in practice. In the reality of the existing healthcare and social care system, this right often remains only a possibility that most patients and their family members can never experience. In the present moment structure of palliative care network follows the structure of healthcare system. Serbian healthcare system is organized as “decentralized star network” (Galloway, 2010:288) with four central nodes (tertiary healthcare institutions – clinical centres) around each are organized smaller star network of different (secondary and primary) healthcare institutions. However this network is not equally available to all citizens of Serbia. Those who live outside central nodes, in smaller towns and villages, who are in particularly difficult condition that requires more frequent therapy changes, who are not capable to move independently … etc are more depend of the quality of the palliative care that could receive within their homes. But, the capacities of Serbian healthcare system to offer that kind of supply is limited.

In the Republic of Serbia, the legal framework for palliative care relates to the Law on Health Care, the Law on Health Insurance, the Law on Patients' Rights and the Law on Social Protection. The strategic framework is envisioned in the Strategy of Public Health in the Republic of Serbia 2018-2026. and the Strategy for Palliative Care with Action Plan 2009 which expired in 2015, and Regulation on the National Program for Palliative Care for Children in the Republic of Serbia.

During 2015, 21,375 residents of Serbia died of cancer. In 2020, 49,043 malignant tumours were registered in Serbia, according to data from the International Agency for Research on Cancer of the World Health Organization.

In the year when almost 115,000 people died in Serbia, according to the data of the Republic Institute of Statistics, cancer claimed 28,107 lives - according to WHO data. Compared to the previous year, a growth of 13.99 percent was recorded. (in 2019, the number of deaths was 100,963).

Family environment can also be provided by persons who are not related to the child. The above data suggest that out of the estimated 1.5 million children and adolescents aged 0-19 1,500- 2,400 may have indications for palliative care, of which 170-540 die each year (150-200 deaths inthe neonatal period, and 250-300 in later age).

The proposal of the National Program for Palliative Care of Children was adopted by the Government of the Republic of Serbia on April 4, 2016 and normatively formulated with the publication of the Regulation on Palliative Care of Children in Serbia. With this, Serbia has become one of the European countries that respect children's rights, including the right to early childhood education.

Some earlier studies by the WHO considered that 80% of cancer patients require palliative care during the last year of life, which brings us to the number of 12,600 cancer patients who would need palliative care in Serbia. Along with this number, it should be kept in mind that many family members of these patients will have a smaller or greater need for psychosocial support that is part of palliative care.

When it comes to accommodation capacities for palliative care, the recommendations from the Strategy and especially not the recommendations of the White Book have not been reached. In some regions, the situation is better and there is an approximate number of beds in the established palliative care units, but there are also those regions where there is not a single palliative care unit, but possibly the number of designated beds per hospital, but this by no means implies quality palliative care in in those areas where there are PZ units, the question of good practice in this area is raised.

The strategy and plan of the network of health institutions, where there is 1 team for home treatment for every 25,000 inhabitants. These teams are primarily established to carry out extended hospital treatment for those patients who are no longer suitable for hospital treatment but are still too weak to come to their chosen doctor at the health center. If we go back to the data that 5,432 cancer patients died in Belgrade in 2015 and that around 90% of these patients required palliative care during the last 6 months of life, it means that there were 4,889 patients who needed palliative care. Further calculations show that 93.12 doctors and nurses were needed for these patients, which means that palliative care for oncology patients was approximately 27.

For rural areas, it is provided that a professional (doctor or nurse) can make 4 visits per day, and it is also provided that in these areas the home treatment team, if it exists, consists of 1 doctor and 5 nurses. In any case, the figures recorded as the number of professionals for palliative care in home conditions in other areas, except for Belgrade, predicted 4 home visits per professional per day, without going into the details of how many professionals the team actually has and what their professions are. about the possibilities of visiting 4 patients due to geographical dispersal and inaccessibility of the field.

In the entire territory of Serbia, there is a lack of social protection services that provide palliative care in accordance with good international practices - a holistic approach and integrated services. The necessity of recognizing palliative care as a part of the social protection system is indicated by the Research on the difficulties encountered in securing the right to primary health care for insured persons who are beneficiaries of home accommodation for adults and the elderly in the social protection system.

Since there are no nursing home-type social institutions, many patients are placed in geriatric institutions when they no longer need hospital treatment and it is not possible for them to stay at home, usually for social reasons. Most geriatric institutions accept patients with advanced oncological diseases, some of them are in advanced stages of the disease, but do not provide them with palliative care in an integrated manner, which implies a comprehensive approach to the patient and family, the work of multidisciplinary teams that include doctors, nurses, social workers, psychologists, physiotherapists, clergy, and others. It is necessary for palliative care to be systematized and included in the social protection program, to be implemented as a program activity or several of them within the existing services. There is a place for palliative care within the existing service of home help, day care, accommodation (respite accommodation, home accommodation.

Local administrations should integrate all services (health system, social protection, CSOs) into this model in their local development service plans. Services should be developed based on the needs of patients and family members.

Needs for palliative care in Montenegro

On the legislative level government of Montenegro recognises the importance of availability of general healthcare services and palliative care as one of its important parts. This is evidenced by two documents adopted by the Montenegrin government in the last 10 years - Master Plan for Health Development of Montenegro 2015-2020, Ministry of Health of Montenegro (Master plan razvoja zdravstva Crne Gore 2015-2020, Ministarstvo zdravlja Crne Gore) adopted in 2015, and National Cancer Control Program, Ministry of Health of Montenegro (Nacionalni program za kontrolu raka, Ministarstvo zdravlja Crne Gore) adopted in 2011. In one of them it is said:

Even though in terms of legislation, state of Montenegro recognises the need to organise the service of palliative care for this extremely vulnerable category of patients, and also the rights of patients to get palliative care if they suffer from incurable diseases2, especially for cancer patients.

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[2] This is also supported by the following documents: (1) *Master Plan for Health Development of Montenegro 2015-2020*, Ministry of Health of Montenegro (*Master plan razvoja zdravstva Cene Gore 2015-2020*, Ministarstvo zdravlja Crne Gore) adopted in 2015, and (2) *National Cancer Control Program*, Ministry of Health of Montenegro*(Nacionalni program za kontrolu raka*, Ministarstvo zdravlja Crne Gore) adopted in 2011. In these documents palliative care is explicitly referred.

The both documents address the importance of establishing palliative care as an integral part of the health care of cancer patients.

Among other things, the Master Plan states: "Palliative care (care). According to demographic and epidemiological trends, the number of elderly and chronic patients is increasing, the image of the traditional family is changing, which has caused a different approach to the problem of death. The obligation to care for the elderly, chronically ill and dying patients has been transferred from the family to society and, to the greatest extent, to the public health system. Palliative care for patients with a progressive and incurable disease and their environment means integral care (care) due to the consequences of the disease (pain, nausea, difficulty breathing, exhaustion, delirium) and psychosocial needs for the highest possible quality of life until death. This includes those suffering from malignant diseases, organ failure, neurological diseases, psychiatric diseases, HIV and others. Today, palliative care takes place partly at the primary level, through the services of a visiting nurse and home treatment by a selected doctor, which does not meet real needs. In the coming period, in the field of palliative care, it is necessary to pay special attention to the development of educational programs and the organization of multidisciplinary teams for palliative care (doctor, nurse, social worker, physiotherapist, occupational therapist, dietician andpsychologist). Palliative care must become an integral part of integral health care throughpalliative teams, palliative departments or hospices. Also we should pay special attention to the development of educational programs and the organization of multidisciplinary teams for palliative care (doctor, nurse, social worker, physiotherapist, occupational therapist, dietician andpsychologist).

Within Priority 1 of the Master Plan, secondary and tertiary health care should include ambulatory-specialist treatment, acute and sub-acute hospital treatment. Thanks to the changed demographic structure and advances in technology in medicine, it is necessary to introduce new forms of patient care (day hospitals, non-acute care, extended hospital care, palliative care). If we want to respond in a timely manner to the needs and wishes it would be necessary to make additional efforts to find a solution that would establish stronger links between different parts of the system - healthcare institutions and centres for social care, primary healthcare institutions and those in the field of secondary and tertiary healthcare - between the selected family doctor, from the local healthcare centers and home treatment services, and a doctor-specialist who, within the institution of secondary and/or tertiary healthcare, diagnosed the disease and monitors the case of a particular patient.

Patients in need of palliative care and their family members are (due to the specific cultural context of Montenegro, within which family values such as togetherness, family solidarity and care for community members are highly valued), highly responsive to this, by the legislator, not articulated

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request that imply taking on a significant portion of the burden of palliative care for a dying family member. However, those who experience this, see the need to look for some new solutions:

In the present moment structure of palliative care network follows the structure of healthcare system. Montenegro healthcare system is organized as "centralized star network" (Galloway, 2010:288) with one central node (tertiary healthcare institution – CCM) around which gravitate different (secondary and primary) healthcare institutions. However, in reality, this network is not equally available to all citizens of Montenegro. Those who live outside central node, in smaller towns and villages, especially those on the North, who are in particularly difficult condition that requires more frequent therapy changes, who are not capable to move independently … etc are more depend of the quality of the palliative care that could receive within their homes. But, the capacities of Montenegro healthcare system to offer that kind of supply are limited. In other words, the demand for palliative care is high and the only way in which the existing system of palliative care could fulfil it is to incorporate additional supply outside the institutional system.

The integrated practice of palliative care is not applied due to the lack of public policies, legal regulations, as well as the lack of knowledge of service providers, poor infrastructure and organizational capacities.

The Law on Health Care regulates the organization, implementation and provision of health care, the rights and duties of citizens in the provision of health care, social concern for the health of citizens, the rights and obligations of health workers and health associates, the quality of health care, as well as other issues of importance for the functioning of health care protection. According to Article 25 point 22) of this law, health care activities performed at the primary level of health care include, among other things, palliative care. According to Article 42 of the same law, health institutions that provide hospital health care can also organize long-term - extended hospital care, rehabilitation and palliative care for patients in the terminal phase of the disease.

The Law on Compulsory Health Insurance regulates rights from compulsory health insurance and the exercise of those rights, financing of compulsory health insurance, contracting health care with health service providers, as well as other issues of importance for the exercise of rights from health insurance. In this law, there are no explicit provisions related to health insurance related to palliative care.

The Law on Social and Child Protection is to the greatest extent harmonized with international standards and obligations assumed by the ratification of international treaties, primarily those related to guarantees of human rights and freedoms. The law prescribes basic material benefits and services in the field of social and child protection.

Palliative care is not recognised as a service in social welfare and integrated holistic approach is disregarded.

Article 4 of the Law on Local Governance states that local government can develop services that are of common interest to the local population The municipality also carries out tasks transferred to it by law or entrusted by the Government regulation.

Article 27 line 15 in accordance with the possibilities, participates in ensuring the conditions and improvement of activities: health care, education, social and child protection, employment and other areas of interest for the local population and exercises the rights and duties of the founder of the institutions he establishes in these activities, in accordance with by law.

Needs for palliative care in Albania

According to institute of statistics (2021) the total death rates in Albania is 30,580 and the calculation methodology by Gomez and Stjernsward for palliative care we can project a total of 18,348 patients (30,580*60%) annually needing palliative care. Most people, about 95%, die at home and this is preferable by both patients and their family members.

Based on existing service providers data it is calculated that there should be around 2.500 people out of 18.348 per year, who receive some forms of palliative care service. Those most in need of palliative care services are amongst elderlies suffering from cancer or other life threating illness. Currently palliative care service is provided with limitation in geography, diversity and quality of services from public institutions. Meanwhile in country there are a limited number of association's care that provide mainly home care services to terminal cancer patients across the country. It is evident that these services cannot meet the high demand for palliative care.

A package of policy and legislation documents is available for palliative care in Albania. The policy documents are oriented only to cancer patients and exclude the patients with other diagnoses in need of palliative care.

These documents aren't well known by all the actors in the field, less known it's their content and issues that they address. As result, there are differences in the level of knowledge and the ways of responding to the problems that professionals face during service provision.

Even though there have been distinctive developments, there are still gaps not addressed, especially in the service provision 'responsibilities and the types of services. So, the guidelines for family doctors, define the roles in counseling and informing palliative patients, but don't specifies their role in treatment and home visits. Professionals lack a comprehensive knowledge of the guidelines about primary service. There is uncertainty and confusion in family doctors regarding roles and functions for the service provision at primary service.

The palliative care standards of palliative care service are approved in 2011, but very few professionals know and are informed about, as result they are not implemented. The experts of the area reports the need to review, update and introduce based on an effective strategy to all stakeholders.

Even though the law “On palliative care in Republic of Albania” foresees the care of a caregiver for palliative patients, this is never applied, no concrete actions have been taken to provide regulation at central level. The experts identify the need for social care and the lack of it as an important issue to be addressed. Social administrators reported that in principle the terminally-ill patients are treated as persons with disability and have the right to have caregivers if they fulfilled certain criteria ruled in legislation.

There is no approved reimbursed package that includes not only medicaments but also equipment and medical supplies for patients of palliative care, which in experts’ opinions would facilitate the services to these patients by reimbursing costs they are facing during the illness.

Stakeholders still identify palliative care with cancer diagnose, which is an important gap resulting mainly due to missed actions from policymakers to recognize and integrate within palliative care other diagnosis than only cancer.

The palliative care service in Albania is not unified and the services vary in different regions. It’s a different picture in Tirana, Durres and Korça where the system of palliative care consists, from many years now, of: primary service, OHS (Oncological Home Service), tertiary service (University Hospital Centre “Mother Teresa”) and non-profit service providers such as Sue Ryder Albania and Mary Potter in Korça. The other regions present a different situation with lack of services for palliative care and the service is provided only by family doctors and oncologists specialists at the secondary service.

The territorial coverage with palliative care units is achieved by establishing 11 regional units in regional hospitals in Albania, but not every unit has functioned well.

Other forms of palliative care service as inpatients hospice, respite care, day care centers and do not exists in territory. There are no inpatient units or services dedicated and specialized for palliative care service in Albania. The palliative patients could be hospitalized in emergency situations, but there are not dedicated beds, rooms or units with proper infrastructure resources and holistic approach. Majority of the palliative patients access services by contacting privately medical doctors, paying directly, and receiving service by non-specialized medical staff.

There are only tertiary services for children, located only in Tirana. The other regions lack services for children this due to the low rate of children in palliative care in Albania.

According to legislative framework the provision of palliative care is responsibility of family doctors and palliative care units in hospitals. The family doctors are overloaded and in the majority of the cases can't offer home visits. On the other side palliative care units are established only in the regional hospitals that cover approximately two – four municipalities, so they can't respond properly to all the needs and also do not possess the appropriate resources.

The caseload for family doctors is high and they state that they face long working hours in Albania. From the interviews there are evidences that in some regions the rate is more than doubled than the rate regulated in standards in Albania, which is 1family doctor/2500 inhabitants.

Palliative care service in Albania is outpatient and medical oriented. The model of multidisciplinary team is present only in services such as SOB, Sue Ryder Albania and Mary Potter. This model, even though exists in paper in those hospitals that have palliative care units, practically doesn't function due to the lack of resources.

The only public service provider that offers home care for cancer patients according to a medical-psycho model is located in Tirana. SOB (Home Care Oncological Service of Tirana) is configured and is functioning as a multidisciplinary service and its team consists of 7 doctors, 8 nurses and 1 social worker. SOB serves to a big population and a big territory and can't cover all the needs of Tirana Municipality. SOB offered services to 1300 patients during 2018 and is facing an increasing number of patients.

The access of population to palliative care services is very low because all the services are located in Tirana. Palliative care units are suffering lack of resources and they are not doing home visits anymore, and there are regions that have no palliative care units at all. The rural population and the people with limited financial resources are the ones who are almost without access due to the distant services which are located in cities.

The interviewed medical doctors reported that they know very little about the patients' rights and even though in their understanding there is a linkage between the palliative care system and Human Rights, they don't see the palliative care system to reflect it.

In the primary care service, except of SOB established in Tirana, the public service are medical oriented services, composed only by nurses and medical doctors. The family doctors service consist in the prescription of the medicaments (reimburse or not), informing and instructing the patients relating disease and medicaments and in rare cases perform home care service. The family nurse by regulations should do home care service for palliative patients, but in reality the number of home visits is limited.

Secondary care, in the regional hospitals since many years are established the palliative care units with two – four beds capacity. They aim to provide day care and home care service to palliative patients. In the very begging there were several efforts which resulted in creating a model and provision of home care with day care service. Actually these units are functioning mainly as day centers for a number of limited patients.

The regional hospitals in Albania have one social worker or psychologist who is responsible for all units, but mostly they are engaged in the pediatric and maternity care. Therefore the palliative care services lack the presence of these professionals, even is supposed to be a multidisciplinary team. Health staff recognizes the complexity of patients; needs and they ask for collaboration and support by social care services of municipalities.

Referral system is working according to the services available in the region, anyway the referral system consists of: family doctor (primary), oncologist specialist (secondary), Oncologic Hospital (Tirane, tertiary). Wherever is available, family doctors refer the patients and/or familiars to home care services offered by public or non-profit service providers (Tirana, Durres, Korce).

Limited diversification of the services is verified. The main services are counseling services and geographic limited home care service. There are present day hospital services. The palliative care units that were established at the regional hospitals (at the beginning they were offering home care services) nowadays are operating as day hospital services due to the different understanding about palliative care of hospital managers and they are not offering anymore home visits.

The patients are asking for home care visits in the informal ways, and they are getting it from not qualified health staff and not through the system. Majority of the patients or their familiars get the service by direct payment or using acquaintances' networking.

There is a lack of inpatient services for terminally ill patients or number of beds in hospitals for palliative care. The rate for availability of beds in hospitals is 2/1000 inhabitants in Albania. The interviewed health staff stated the lack of beds for palliative care in years in Albania.

Palliative care is an approach that improves the quality of life of patients and their families and is related deeply with the actions made by state to guarantee and respect Human Rights of the patients. Albania has made distinctive efforts to produce legislation, regulations and strategies for palliative care. Actually, there is no strategy in force due to the end of time period of the previous strategy (Strategy of Palliative Care in Albania 2010-2020). As result, there is no Plan of Action. There is an identified need to revise the standards and protocols of palliative care.

Palliative care is not fully recognised under the human right to health. There is a situation of withhold care in terms of geographically differences of law implementation, drug availability, accessibility and affordability.

The system doesn't respond to the needs of patients in palliative care due to the organization of the system, lack of services, lack of resources. The number of patients in need of palliative care in Albania is increasing and the projected number of patients/year will put the system in crises or will seriously endanger the access of patients for services.

The patients with other diagnosis than cancer do not receive palliative care and are excluded de facto of the system.

There is a limited typology of services, which affects the right to health services and especially the inpatient services result in a very low availability of beds in all regions.

Palliative care services are out patient oriented, the situation is not responded with more home and community services, but the main burden is of patients and families. Inpatient services present lack of beds and lack of access of hospital palliative care in many regions.

Palliative care in Albania is not provided as an integrated health services, the public services are mainly medical oriented. Medical needs are more in focus and less psychosocial needs of patients.

The multidisciplinary team approach is not present everywhere to address practical needs and provide different services. But there is an articulated need from all professionals to work as a team and they recognize other professionals' contribution to the needs of the patients.

The patients are benefiting only drug reimbursement treatment and completely lacking the medical equipment and supplies/facilities, which is covered by patients and their families and is considered as a expensive service to be paid privately.

Palliative care in Albania is more identified with cancer diagnosis and less with other diagnosis as chronic diseases, AIDS, diabetes, kidney failure, chronic liver diseases, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis, etc.

Pain treatment has changed a lot in Albania regarding the mentality of medical doctors and patients. The family doctors are prescribing more opioids but they still have barriers to prescribe them, which creates problems in terms of access the right for a life without pain and respect to person's dignity.

Although there are no evident problems with drug availability, it's verified insufficient accessibility and affordability which are related with the different implementation of the law in territory, limited access to prescribe opioids from family doctors, lack of human resources and lack of staff training in palliative care.

Palliative care is frequently delivered by non-specialists or other specialist doctors from different disciplines than oncology or palliative care, contacted based on private acquaintances/referral or by directs payment due to the limited home care services in country.

Mapping of the needs and potentials

Mapping should be divided into four phases: 1) pre-mapping; 2) mapping; 3) undertaking actions; and 4) analysing and evaluating mapping efforts.

It is important that local government designated a coordinator who would be in charge to lead the process from the beginning.

The pre-mapping envisions identification of the stakeholders to lay the groundwork for productive collaboration and to establish a clear vision and goals for building the system.

Stakeholders are essential for the development of systems and the design of projects and plans.

Composition of the stakeholders: During identification phase stakeholders should be carefully selected from people that represent health, social sector, local government, NGO service providers or human rights that work with or represent vulnerable groups of citizens that have life limiting illnesses. Number of stakeholders should be decided upon role and interest of the people to be engaged in the process. Stakeholders can be divided in different groups, such as users and beneficiaries or governance and regulators. Gaining an understanding of the influences, interests and attitudes of the stakeholders towards the project and the importance and power of each stakeholder.

During the pre-mapping step, key stakeholders will be identified and secured to define the vision and goals for aligning community resources.

During pre-mapping process clear communication should be established in the beginning will make it easier to achieve long-term goal of aligning and streamlining community resources.

Mapping process: Mapping process should be realised through the workshops.

Workshops should be organised upon sector bases and specific sector groups of stakeholders.

Mapping, determines which resources should be mapped and how best to map them.

Collecting and analysing data at this point helps stakeholders identify strengths and challenges. In this view it is important to identify a) needs of the population that have cancer and other life limiting illnesses and barriers which they encounter b) identify potentials of each sector including infrastructure, services, human resource trainings or employment c) key national policies and local policies that comply or make barriers for implementation of services or desired processes.

The mapping process begins by selecting one goal or high priority to map. The usefulness of resources is determined by evaluating the extent to which they assist in meeting strategic goals and objectives. This stage involves selecting a focus, identifying, and collecting data or resources, and analyzing the data or resources collected.

Analysing data obtained from the mapping process: Acting on the information from the mapping process is an important step.

The misconception exists that once resources are identified and mapped. Needs should be carefully planned to be translated into actions and translated into Action Plan.

Local Action Plan composition and process

Local Action Plan for Palliative care improvement should have achievable actions, each designed to improve the care patients receive and increase the efficiency of health and social care services, ensuring the palliative care system can cope with the accelerated demand.

The Action Plan advocates a holistic approach to improving the provision of palliative care, identifying challenges and solutions across the health and social care system.

It recommends reforms to the care delivered in hospitals, hospices, care homes, patients' homes and in the community, as well as calling for an overhaul of the education and training for health and social care professionals, and greater investment in research.

Examples of the Local Action Plan for Palliative care development of municipality of Užice

ACTION PLAN FOR DEVELOPMENT OF PALLIATIVE CARE IN CITY OF UŽICE FOR THE PERIOD 2022-2026

LEGAL BASIS, THE BODY THAT DEVELOPS MEASURES

Based on the analyses of the legal framework, local self-governments can create services on the local level that will meet the needs of citizens and enable a better quality of life. Normative acts that ensure the possible development of Palliative Care (PC) on the local level are: National strategy for palliative care in the Republic of Serbia 2009-2015.

Article 60 of the Law on Social Protection states that social-health institutions can be established for beneficiaries of specific health status who have the need for both social care and permanent health care or supervision, and Paragraph 2 of the same Article defines the formation of special social-health organisational units within social protection institutions, i.e., within health institutions[1].

Article 65 of the Law on Health Care regulates primary health care, which among other things includes treatment, follow-up visits, health care and rehab at home (Paragraph 6); prevention and early detection of the illness, health care and rehab for persons placed in health care institutions (Paragraph 7), mental health protection (Paragraph 11), while Paragraph 12 emphasises palliative care[2]. The mention and analysis of this article of the Law on Health Care is of particular importance as it refers onto the preventive purpose of health activities and health response at the primary level, when prevention is possible, that is when it is in the best interest of the patient to remain in his primary environment. Furthermore, Article 66 of the same law states that "health institutions cooperate with other health, social, education and other institutions and organisations in the implementation of health activities at the primary level of health care, for the purpose of preparing and implementing programs for health preservation and improvement." [1]

Article 58 of the Law on Social Protection precisely defines the following: „Depending on the needs of beneficiaries, social protection services can be provided simultaneously and in combination with services provided by education, health and other institutions." In this respect, it is essential to make the services available for beneficiaries. Through Article 8, Paragraph 2, the Rulebook of organisation, norms and work standards of centres for social work defines that the Centre for social work ensures the availability of services „by coordinating activities with other public services, charity organisations, citizens' associations and other organisations in the local community."[2] The role of the Centre for social work as a key institution in the social protection system is, among other things, to provide the entire support network for the beneficiary of the system, which requires established cooperation with health, education and other relevant services, as well as referrals between them.

The institutional framework for provision of health care is defined by the Law on Health Care, Article 28, which precisely lists all relevant health care institutions and services at the primary, secondary and tertiary level of health care: "A health care institution can be established as: a health centre, health institution polyclinic, a pharmaceutical institution, a hospital (general and specialised); a medical centre; an institution; a clinical hospital centre; an institute; University – hospital centre; a military health institution or a medical unit and institution within the Serbian Military Forces, in accordance with a special law.[2]

The social protection system is institutionally defined by the Law on Social Protection, and Article 10 of the law states that social protection institutions are established with the aim of realizing rights in the field of social protection and providing social protection services established by this law, in order to carry out development, research, advisory and other professional work in social protection and to realize other interests established by law.[2] The main institutional link in the provision of services and realizing the rights of beneficiaries is the Centre for social work, founded by the local self-government unit. It is crucial to have different services available for potential beneficiaries at the local level. Where they do not exist, the Law on Local self-government regulates the possibility of inter-municipal cooperation, Article 88 – The unit of local self-government, its bodies, and services, as well as the companies, institutions and other organisations by which they are founded, cooperate and join forces with other units of local self-government and its bodies and services in areas of common interest and they may pool resources and form joint bodies, companies, institutions and other organisations and institutions for the purpose of achieving them, in accordance with the law and the statute.[2]

DESCRIPTION OF THE CURRENT SITUATION

General information

According to the level of development of local self-government units, the City of Užice belongs to the first group whose development level is above the national average level.

According to the 2011 census, 78,018 inhabitants live in the City of Užice, on an area of 667 km², so the average population density is 117 inhabitants/ km². 75% of the total population lives in the urban area, and 25% in the suburban area. According to the 2002 census, the average age of Užice residents was 39.2 years (38.3 for men and 40 for women). By looking at the data on the movement of the population around the Zlatibor district, it can be concluded that the number of inhabitants in Užice decreased by -2.7% between the three censuses. A trend of emigration to larger cities (Belgrade, Novi Sad) is evident, especially among the young, highly educated people. According to the results of the census, 24,745 families were recorded. Out of the total number: 27.5% are families without children, 32% are families with one child, 37% with two, 3.5% with three, 0.2% with four, while only 0.06% have five or more children. 56% of the families have children under the age of 25. Structure as per level of education – according to the available data of the RIS, the structure of the population aged 15 and over according to the level of education is as follows: 5% of the population has no education; 37% has completed primary school; 49% has completed secondary school; 5.2% has higher education and 6.2% holds a university degree.
The adult population counts 66,626, while there were 5,191 preschool children out of the total number; 40,023 persons count in the active population. Active population – population aged 30 to 65 represents 51.51% of the total population. Young people, aged to 29 represent 12.71% of the total population. The dependent population, i.e., inactive, is represented by, while children up to 15 years of age represent 19.09% compared to the total of 26.6% (children – 19.09% and the elderly over 65 represent 16.7% of the population). 98% of the total population are Serbian. In addition to the Serbian population Montenegrins, Yugoslavs, Croats, Roma, Macedonians, Muslims, Slovenians, Hungarians, Russians, Bosnians, Slovaks, Bunevacz, Russians, Albanians, Germans, Ukrainians, and Bulgarians also live in Užice. The average population density is 105 per square kilometre; Population growth is negative -5; Human birth rate 9; Death rate 14. Employment – Analysing data on the structure of employees according to sectors of activity, we can conclude that: (1) 10% are employed in the field of transport and communications, (2) 14%in the field of health and social work, (3) in the manufacturing industry, (4) 9% in construction, (5) 7% in education, (6) 9% in wholesale and retail trade and (7) 4% in state administration (institutions and companies) and social insurance.

The action plan for improvement of palliative care in Užice is a document which determines measures for the improvement of palliative care in Užice for the period from 2021 to 2026. To improve the care of patients diagnosed with incurable illnesses and to provide support for their family members in overcoming the difficult circumstances because of the illness of their loved ones. This plan was created through the cooperation of the local self-government of the city of Užice and the BELhospice organisation through the project „Strengthening the effectiveness of local self-governments and strengthening the capacity of professionals in the field of social protection in order to better respond to the needs of vulnerable groups and the challenges they face during the COVID-19 pandemic" and which is implemented by BELhospice with the support of the German development organisation GIZ.

The creation of the Action Plan was carried out in two phases. The first phase included the mapping of existing social and health care services in the city of Užice. The second phase included the analysis of these results and the formulation of priority measures with the aim of improving palliative care in the city of Užice and ensuring a better quality of life for citizens suffering from an incurable illness.

The mapping of services involved several stages: a) defining international and national norms for the development of integrated social protection services, b) creating a situational analysis of existing resources-infrastructure, social and health care services, c) the need for education of service providers to enable better quality of life for vulnerable groups, d) conclusions and recommendations for the development of palliative care.

In the first phase, through the desk analysis, international and national norms, and local policies for the development of integrative social protection services were identified using primary and secondary resources of available information and literature. In the second phase, two workshops were organised in the city of Užice, and attended by representatives of the local self-government, institutions from the social and health care system, as well as representatives of civil society organisations (CSOs). The key issues discussed at the workshops included defining the available capacities/institutions of social and health care and CSOs (infrastructure, personnel, training, etc.) to respond to the needs of vulnerable groups. The second workshop was attended by representatives of the local self-government and representatives of social and health care institutions to discuss priorities and proposed solutions/measures for the improvement of PC in the city of Užice.

The starting point for improving the position of citizens from vulnerable groups suffering from an incurable illness and their family members is reflected in the need for integrated social and health care services. These services are an opportunity to develop palliative care at the local level. Through integrated services, individuals in need of health and social care services are evaluated in total, enabling them to reach and maintain a quality and dignified standard of life and the possibility to go through certain stages of the illness in as little pain as possible. The expediency of integrated services such as palliative care is reflected through multisectoral cooperation and networking of social and health care systems to ensure comprehensive patient care.

The importance of palliative care

Palliative care is an approach that improves the quality of life of the patient and the family, dealing with problems that accompany life-threatening illnesses through prevention and elimination of suffering through early detection and precise assessment and treatment of pain and other problems: physical, psychosocial, and spiritual. [2] The term „life-threatening illness" refers to patients with an active, progressive, advanced illness with a limited prognosis. These illnesses include (atherosclerotic changes that lead to an increase in the number of people suffering from cardiovascular diseases, malignant diseases, chronic obstructive pulmonary diseases, diseases of the musculoskeletal system, osteoporosis as the main cause of disability in the elderly, neurological disorders).

In the broader sense, palliative care is a type of health service that, within the framework of the social security system, represents the care of both the patient and his family through provision of psychosocial support, and refers to the period from the diagnosis to the period of mourning because of the loss of a family member. This service assumes the concerted efforts of a highly trained and adequately formed multidisciplinary professional team consisting of health workers (doctor, nurse/technician), social worker, psychologist, spiritual coordinator, and volunteer. The main goal of palliative care is to prevent and alleviate suffering, as well as to achieve, improve and preserve the quality of life of people who are faced with serious, incurable illnesses, as well as their families.

The intertwining challenges faced by an individual in need (the need for medical care and the involvement of social services) requires their presence, referral of different professional services onto each other and standardization of taken actions depending on the individual needs of the beneficiary.

Description of the current situation

Palliative care is organised in the special unit of the General hospital of Užice in Požega. The capacity is for 12 people, the building is physically separated from the Chest and Internal departments. There is a home care and treatment service at the Užice health centre, that includes a field visit of doctors and technicians. Pain therapy, symptomatic therapy, is prescribed, urinary catheters are placed and changed. Since the vaccination against COVID started, the teams vaccinate the beneficiaries within their home visits. The home care service is designed to cover patients from rural areas as well. Cancer patients are treated at the Oncology service in Užice, and patients from **all ten municipalities** of the Zlatibor district gravitate towards this service. The service consists of the Day Care Hospital and the Department of Medical Oncology. For the „C" list treatment patients are referred to Kragujevac and Belgrade (depending on type of therapy).

Social protection is provided through a partnership network of the public and civil society sectors that provides a range of institutional and non-institutional services to citizens in rural and urban areas of the city. The main institutions operating in this area are: the Centre for social work, Home care department of the Centre for social work – old people's home in Zabučje, City centre for local services, Red Cross and over 10 civil society organisations that are directly or indirectly involved in the provision of social protection services. In the previous period, the city of Užice significantly improved the social protection system by developing new non-institutional social protection services: day care for children and young people with developmental disabilities, help at home for the elderly, help at home for children and young people with developmental disabilities and people with disabilities. In the City Centre for provision of social protection services, the tasks of planning and implementing social protection services are carried out, which improve the position of children and young people from vulnerable social groups, adults and the elderly living in the territory of the city of Užice. Since its establishment, the Centre has taken over the services „Help at home for the elderly" and „Day care for children, young people and adults". Since September 2019, the Centre has also been providing the „Child's personal companion" service.

Population aging trends and an increase in the number of patients suffering from malignant and other incurable illnesses, as well as the challenges brought by the corona virus, require the improvement of palliative care services. It is thus necessary to adopt measures that enable the quality and accessibility of treatment for patients diagnosed with incurable illnesses and their families through the improvement of services provided by health and social institutions.

Defining the problem

Measures for improvement were formulated based on identified problems that need solving as soon as possible to improve palliative care services in the municipality of Užice. Underdeveloped infrastructure capacities of health institutions in the local self-government of Užice.

Palliative care is organised in the special unit of the General hospital of Užice in Požega. The unit has the capacity for 12 people, yet the needs are greater. Patients suffering from cancer are treated at the Oncology service in Užice, and patients from all ten municipalities of the Zlatibor district gravitate towards this service. The service consists of the Day Hospital and the Department of medical oncology. There are not enough beds to accommodate all patients in need of palliative care, especially those with neurological and mental illnesses.

The palliative care unit in Požega at the General hospital of Užice does not have enough bed capacity to admit all beneficiaries in the terminal stage of the illness. Emotional and spiritual aspects of patient care are included sporadically. The plan envisages the inclusion of a psychologist, a social worker, and a spiritual coordinator but this has not been organised yet.

Insufficient number of employed professional staff in the General hospital to work with patients in the terminal stages of the illness

There is an insufficient number of oncologists and other doctors, nurses, physiotherapists, psychologists, and social workers according to the expressed needs of beneficiaries. Beneficiaries are referred to Belgrade and other health centres for treatment of severe illnesses.

There are no specialist palliative care teams for home care of terminally ill patients.

The number of employees in the Home care services is smaller than is necessary, which affects the workload of existing staff members and the quality of service provided to beneficiaries. Home care staff, doctors and nurses currently provide home care services to all patients.

Social protection services „Help at home" and „Day Care Centre" do not have adequately developed programs aimed at specific vulnerable groups with a holistic approach aimed at beneficiaries and family members and the work of multidisciplinary teams.

It is necessary to develop programs and strengthen the existing staff members of the City Centre who can provide training to other local self-governments and service providers.

Social protection services are not sufficiently developed according to the needs of beneficiaries living with incurable illnesses

The department for accommodation of adults and elderly persons in Zabučje is a social protection institution for the accommodation of adults and elderly persons, with a capacity for 80 beneficiaries, established at the Centre for social work „Užice" in 2011. The institution provides housing, nutrition, care, primary health care, social work services, cultural, entertainment, recreational, occupational, and other activities, depending on the needs, abilities, and interests of beneficiaries. A great number of beneficiaries have a diagnosis of an incurable illness. Therefore, it is necessary to create an adequate infrastructure, to introduce quality standards for working with beneficiaries in need of palliative care, and to harmonize personnel solutions and training of staff according to the needs of beneficiaries.

Lack of multidisciplinary team specialists who possess specialised knowledge and skills in the field of palliative care

It is necessary to train professionals, social workers, doctors, nurses, psychologists, and volunteers, about the approach and practices of support for vulnerable groups of patients and their family members.

Lack of integrated social and health services, intersectoral and intermunicipal cooperation

The Rulebook on detailed conditions and standards of social care services[3] requires a minimum standard which does not include the medical part of care. Bearing in mind that over

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[3] https://www.paragraf.rs/propisi/pravilnik-blizim-uslovima-standardima-pruzanje-usluga-socijalne-zastite.html

60% of beneficiaries in state and private social care institutions need palliative care, it is necessary to integrate the medical part within the standard to ensure the quality of service for beneficiaries.

There is no coordinating body that would perform tasks at the regional level. It is necessary to establish intersectoral cooperation for the implementation of intersectoral (integrated) social and health care services at the regional level. It is necessary to create service programs in cooperation with the municipalities in the Zlatibor district, coordinated according to the needs of the inhabitants of the region.

Lack of administrative capacity of civil society organisations in the development and provision of services to vulnerable groups

Civil society organisations have a great influence on the development of palliative care. The Counselling centre for women with disabilities suffering from breast cancer „Jefimija“, the City Association of the blind and visually impaired in Užice, the Association of the Dystrophies of the Zlatibor district – Užice, the Association of the Deaf and Hard of Hearing of the Zlatibor District, Užice, Multiple Sclerosis Association of the Zlatibor District of Užice, Association of Paraplegics of the Zlatibor District, Red Cross and others. It is necessary to strengthen their capacities in defining services, research activities, animating volunteers to provide support to vulnerable groups, conducting public campaigns to raise awareness.

Organisations do not have permanent source of funding to enable the continuity of providing this support service to patients living with incurable illnesses and their family members.

Goal: *Create an Action Plan to improve and achieve the best possible quality of life for patients diagnosed with incurable illnesses and their families*

ACTION PLAN OF MEASURES FOR IMPROVEMENT OF PALLIATIVE CARE

Goal	Measure	Expected results	Activity holder	Link to local planning document (or legal and national framework)	Financial resources	Deadline
1. Improve and achieve the best possible quality of life for patients diagnosed with an incurable illness and their families	1.1. Creation of technical design	1.1.1. The technical design envisages an increase in bed capacity for patients requiring palliative care	General hospital of Užice	Development plan of the city of Užice	General hospital of Užice	Until December 2022
	1.2. Organise the adaptation of the General	1.2.1. Increased number of beds and enabled	General hospital of Užice	-Development plan of the city of Užice	General hospital of Užice	2022-2023

	hospital in Užice	timely access to treatment of patient, secured rooms for patients according to illness category		-Strategy of palliative care of the Republic of Serbia		
	1.3. Adaptation and increase in the number of beds in the palliative care unit in Požega	1.3.1. Increased number of beds for patients living with incurable illnesses in the terminal stage	General hospital of Užice	Development plan of the city of Užice– 0,04 per 1,000 inhabitants and a team consisting of one medical doctor specialising in internal medicine and five nurses per 10 patients	General hospital and donors	2022-2024
2. Increase the number of qualified staff in the General hospital for provision of PC services	2.1. Employ specialist doctors, nurses, psychologists, physiotherapist	2.1.1. Improved quality of services and increased satisfaction of beneficiaries	Systematization of work positions	Decision on the systematization of work positions	General hospital of Užice	2021-2025

	s to work with patients and family members	2.1.2. Reduced workload of the existing staff 2.1.3. The needs of staff members adjusted according to the number of patients suffering from severe illnesses and not according to the number of inhabitants				
3.Train the team to work with patients in need of PC	3.1. Organise specialist training for new staff members to work with patients and their families: Control of pain symptoms, providing	3.1.1. Teams trained to provide a holistic approach to support patients and family members	Ministry of Health Accredited specialist training for PC		General hospital of Užice	2022-2023

	psychosocial support to the patient and family members					
4. Increase the number of employees in the Home care service	4.1. Form a specialist team to provide services to patients diagnosed with incurable illnesses	4.1.1. Adequate care available to all patients 4.1.2. A specialist team of doctors and four nurses are trained and provide services according to the needs of patients in all areas of the municipality	According to the existing norm of: one doctor and four nurses per 25,000	The Rulebook on detailed conditions for the performance of health care activities in health care institutions and other forms of health care („Official Gazette RS, no. 43/06) Article 65 of the Law on Health Care regulates primary health care, which among other things, includes treatment, follow-up visits,	General hospital of Užice	2022-2025

				health care and rehab at home (Paragraph 6); prevention and early detection of the illness, health care and rehab for persons placed in health care institutions (Paragraph 7), mental health protection (Paragraph 11), while Paragraph 12 emphasises palliative care		
5. Adaptation and improvement of accommodation facilities in Zabučje	5.1. Adapt accommodation capacities according to the category of beneficiaries	5.1.1. Improving the quality of work 5.1.2. Increased number of beds 5.1.3. Obtained use permits	Local self-government	Development plan of the city of Užice	Local self-government Ministry of Labour, Employment, Veterans and Social Affairs	2022-2023

6. Create a program of socio-health services in social protection institutions	6.1. Introduction of multidisciplinary teams in the work of institutions and introduction of integrated service standards	6.1.1. Introduction of standards according to the needs of beneficiaries and international practices	Local self-government, CSW, Management, Institution	Strategy for the development of social protection of the city of Užice 2021 – 2025	Ministry of Labour, Employment, Veterans and Social Affairs	2022-2023
7. Provide support for caregivers caring for seriously ill family members	7.1. Development of a psychosocial support service for caregivers	7.1.1. Improved quality of life if informal caregivers	Local self-government, Social protection institutions, Centres for social work	Law on social protection	Ministry of Labour, Employment, Veterans and Social Affairs, Local self-government	2022-2023
8. Improve the capacities of professionals in CSW working with vulnerable groups which need palliative care	8.1. Provide training for professionals in CSW, and institutions working with vulnerable	8.1.1. Improved knowledge and skills of professionals	Local self-government, social protection institutions, Centres for social work	Social protection development strategy	Ministry of Labour, Employment, Veterans and Social Affairs	2022-2023

	groups which need palliative care	8.1.2. Improved quality of service and comprehensive approach in providing palliative care				
9. Provide Day Care services for children diagnosed with incurable illnesses	9.1. Establishment of a Day Care Centre for children diagnosed with incurable illnesses	9.1.1. Program of services created 9.1.2. The quality of life of beneficiaries and caregivers improved	Local self-government	Development plan of the city of Užice	Donors	2022-2025
10. Inform the public about the importance of palliative care	10.1. Create a campaign in the media 10.2. Production of promotional material	10.1.1. The number of surveyed citizens before and after the campaign who recognize the meaning of palliative care	General hospital of Užice Local self-government City Centre for social protection services	Development plan of the city of Užice		2022-2025

11. Involve civil society organisations to improve the quality of provided PC services, Red Cross, Jefimija and Association of Paraplegics	11.1. Strengthening the capacities of CSOs to provide integrated services	11.1.1. Improved cooperation between CSOs and beneficiaries 11.1.2. Partnership cooperation established between CSOs and LS	City Centre for social protection services	Development plan of the city of Užice		2022-2025