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# THE ROLE OF NON-GOVERNMENTAL ORGANIZATIONS IN THE MENTAL HEALTH AREA: DIFFERENCES IN UNDERSTANDING

## VLOGA NEVLADNIH ORGANIZACIJ NA PODROČJU DUŠEVNEGA ZDRAVJA: RAZLIKE V RAZUMEVANJU

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**ABSTRACT**

**Introduction.** The contribution's aim is highlighting the differences in understanding non-governmental organizations' (NGOs) role in the mental health area within the public support network for patients with mental health problems from various viewpoints, in order to achieve progress in supporting patients with mental health problems in local communities.

**Methods.** Qualitative data gathered as a part of a cross-sectional study of NGOs in the support network for patients with mental health problems in two Slovenian health regions (56 local communities), carried out in 2013 and 2014, were used. Qualitative analysis of interviews, focus groups and answers to an open survey question was performed.

**Results.** There are differences in understanding NGOs' role in the support network for patients with mental health problems, which stem from the roles of stakeholders (local community officials, experts, care providers, and patients) within this system and their experience.

**Discussion and conclusion.** The actual differences need to be addressed and overcome in order to provide integrated community care. The importance of knowing the current state of NGOs in their life cycle and the socio-chronological context of the local community support network is evident.

**Keywords:**
mental health, non-governmental organizations, community approach, integrated care, collaboration, local communities

***IZVLEČEK***

***Uvod**. Namen prispevka je predstaviti razumevanje vloge nevladnih organizacij v podporni mreži na področju duševnega zdravja z različnih zornih kotov, da bi bil dosežen napredek pri podpori pacientom z težavami v duševnem zdravju v lokalnih skupnostih. Cilj raziskave je bil ugotoviti, katere so vloge nevladnih organizacij, ki jih priznavajo zainteresirane strani v podporni mreži za paciente s težavami v duševnem zdravju, da bi bile prepoznane priložnosti za izboljšanje kakovosti dela in sodelovanje ljudi, ki delujejo v tej mreži. Temeljno raziskovalno vprašanje je bilo: Kakšne so razlike v razumevanju vloge nevladnih organizacij na področju duševnega zdravja v okviru javne podporne mreže za paciente s težavami v duševnem zdravju v Sloveniji z vidika različnih udeležencev?*

***Metode**. Uporabljeni so bili kvalitativni podatki, zbrani kot del presečne raziskave nevladnih organizacij v podporni mreži za paciente s težavami v duševnem zdravju v dveh slovenskih zdravstvenih regijah (56 lokalnih skupnosti) v letih 2013 in 2014, ki je potekala fazno s kombinacijo kvantitativnih in kvalitativnih metod ter z razvitimi instrumenti za zajemanje podatkov s perspektive več skupin udeležencev: uslužbencev v javni upravi, strokovnjakov s področja duševnega zdravja, neposrednih izvajalcev ter pacientov. Za potrebe tega članka je bil oblikovan analitični model kvalitativne analize intervjujev, fokusnih skupin in odgovorov udeležencev na odprta anketna vprašanja, ki je temeljil na tem, koliko so odgovori udeležencev upoštevali znanstveno in politično teorijo o vlogi nevladnih organizacij v podporni mreži za duševno zdravje.*

***Rezultati**. Obstajajo razlike v razumevanju vloge nevladnih organizacij v podporni mreži za paciente s težavami v duševnem zdravju, ki izhajajo iz vloge deležnikov v okviru tega sistema in iz njihovih izkušenj. Sistematično se kažejo v večji ali manjši kritičnosti do nevladnih organizacij z vidika pomembnosti za pacienta ali možnih tveganj. Udeleženci so v skupnem pogledu sintetizirali idealni tip vloge nevladne organizacije, kot je formulirana v znanstveni in socialnopolitični teoriji, vendar pa je razumevanje posameznih interesnih skupin omejeno.*

***Razprava in zaključek**. Treba je obravnavati dejanske razlike in jih premagati, da bi zagotovili celovito skupnostno skrb na področju duševnega zdravja. Pomen poznavanja trenutnega stanja nevladnih organizacij in družbenega kronološkega okvira podporne mreže lokalnih skupnosti je očiten. Obstajajo možnosti za razvoj razumevanja vloge nevladnih organizacij v okviru podporne mreže izvajalcev in storitev na področju duševnega zdravja. Izboljšano vzajemno poznavanje, stalna komunikacija in objektivno ocenjevanje vlog vseh zainteresiranih strani v skupnostni skrbi so priložnosti za sodelovanje med izvajalci, uporabniki storitev in lokalnimi skupnostmi. Prispevek je treba razumeti kot delno analizo neposredne prakse, ki jo je treba preveriti z nadaljnjimi raziskavami.*

***Ključne besede:***
*duševno zdravje, nevladne organizacije, skupnostni pristop, holistična obravnava, sodelovanje, lokalna skupnost*

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## 1 INTRODUCTION

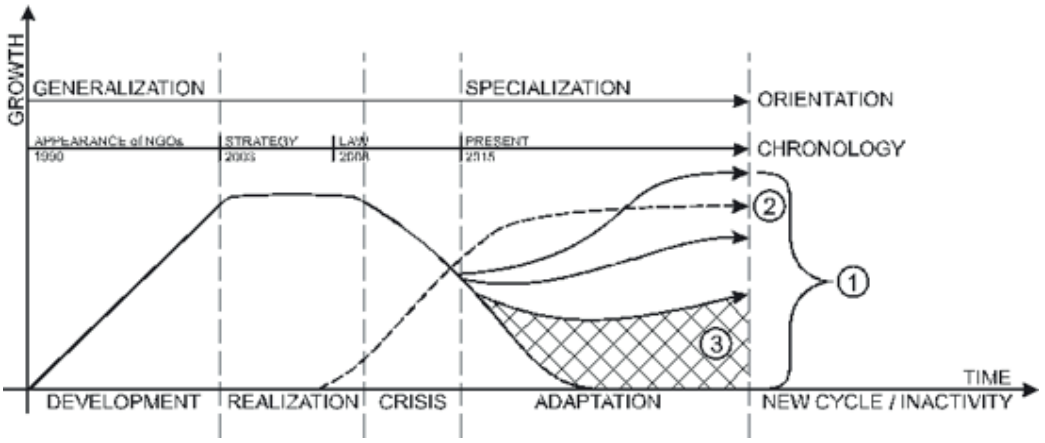
Findings of the Atlas project (1) show that the system of ensuring mental health of the population and care of people with mental health disorders varies from country to country. In accordance with the 'Health 2020', the European health care policy (2), there are increased efforts to develop a harmonized system of coordinated and integrated services (3). Different models have been developed to increase collaboration between stakeholders in the network of providers of care, ensuring (mental) health of a country's (of a region or local community) population, and for a comprehensive support for patient groups (3–5). In this context, the role of non-governmental organizations within the development of community care in the mental health area needs closer attention.

Non-governmental organizations (NGOs) are formally organized, private, non-profit organizations. Their role within the health care system is not always recognized. NGOs mostly differ from public organizations in their vision and mission (aims and objectives), management (professional staff, board members and volunteers), resources (fund raising), reach (public relations, raising awareness in communities, and cooperation), and treatment outcomes (6). Determining the role of NGOs (why and for whom they operate) in 40 countries, Salamon et al. (7) highlighted five groups of roles, namely: the service role (high quality, increased fairness, lower cost/improved efficiency, specialization), innovation role (increased flexibility, accessibility to everyone, the incubator for new ideas, the source of innovation in resolving social and individual problems), advocacy role (changes in government policies or social conditions, advocacy policy, the inclusion of service users), expressive and development role (promotion of cooperation, voluntary work advocate, protecting the interests of various groups, enabling the expression of personal potential, influencing markets by ensuring plurality), community and democracy building role (diversity and pluralism, promotion of mutual trust, belonging and social obligations). Karlsson in Markström (8, 9) demonstrate (using the case of Sweden) the changes in NGOs' roles through the years: from peer support, influencing the official policy, to dedication to the patient's family in order to develop a different view of the ailing family member. They identify the importance of understanding NGOs' roles in the country in order to understand their role within the network of community treatment providers. They emphasize their importance in the planning and decision-making within the health and social care, and in the development of cooperation within care providers' networks (10). Some research confirms that cooperation between public and non-governmental organizations at the primary health care level takes place routinely (11), while others highlights the issue of the lack of knowledge by care providers about NGOs in local communities, and the lack of time to facilitate patients' access to them (12).

### 1.1 NGOs in Slovenia and Their Activities in the Mental Health Area

NGO activity in Slovenia is below the average of comparable countries; Slovenian NGOs are characterized by low levels of professionalization, weak infrastructure, unawareness of the benefits of networking and cooperation, and unsuccessful dialogue with the state and local authorities (13). The John Hopkins' University research comparing NGO activities in 32 countries in 2008 used three indicators: the NGO income compared to gross domestic product (average 5.1%, Slovenia 2.3%), the share of revenues from public sources in the structure of total NGO revenues (average 42%, Slovenia 27.8%), and the share of NGO employees (average 4.9%, Slovenia 0.74%) (14). Data gathered by the United States Agency for International Development (USAID) depict a similar picture (15). There is no data on the actual awareness of people about NGOs, e.g. in the mental health area.

NGOs in the mental health area are community care providers (16), operating at the private level and in the public sphere, as interest groups trying to influence public policy and its implementation (17). Their role within the system is complementary. Research on the organization and operation of the public health service and NGOs in the mental health area in Slovenia has shown an uneven territorial distribution of psychiatric services and health care workers within the network and, consequently, uneven accessibility. It also highlighted inadequate cooperation between governmental and non-governmental institutions (18). An attempt was carried out to create a database of NGOs in the mental health area (19). The chronology of the development of NGOs in the mental health area in Slovenia also shows a significant delay in the development of this sector (9, 20). Figure 1 shows a schematic representation of the development cycle of an NGO in the area of mental health in Slovenia from 1990 onwards.




Legend:
1 – The NGO development cycle
2 – The cycle of an NGO program transfer into the public sector
3 – Basal NGO program, which is non-transferrable to the public sector

**Figure 1.** The life cycle of NGOs in the mental health area in Slovenia (21).

The life cycle of an NGO in the area of mental health includes the following phases: development, establishing/functioning, crisis and adaptation, which may be followed by a new cycle. The role of mental health NGOs in Slovenia was mainly increasing from 2003 onwards, when the Strategy of Cooperation of the Government of the Republic of Slovenia with Non-Governmental Organizations (22) was adopted, up to 2008 and the adoption of the Mental Health Act (16). Formally, NGOs have become a part of the public support network, but continuous financing of their activities was not specified (23). At the same time, new professional profiles in the community care for patients with a mental health disorder (the community care coordinator, community psychiatric care teams) have been established in local community service systems, and some NGO activities have been transferred to them. On the one hand, this is a success of NGOs, but on the other hand, the role of NGOs in the support network began to decrease with the establishment and increased operation of community care coordinators and community psychiatric care teams. For NGOs, the time from 2008 to 2010 was a period of crisis, which may have led to processes of adaptation, preservation of basic programs, realization of new ideas, specialization, inactivity, or reduced cooperation. This is a part of an NGO's normal life cycle, as it has fulfilled its function in accordance with its status as the third sector in the society with its complementary role. The recent period (2010–2015) has seen a new dynamic division of work, which, in its transitional phase, according to Hannigan and Davina (24), includes competition between various professional groups and the emphasis on the professional role and public identity. A characteristic uncertainty in recognizing the roles of various providers, particularly NGOs, is occurring, which affects integration processes. For a more effective complementarity, it is important to know how various stakeholders within the network of providers view the importance of NGOs. According to Mesec (25), the main characteristics of NGOs are flexibility, relative independence, clear activities in the public interest, and close connectedness to communities and groups for whom they advocate and are easily accessible. One of the disadvantages she sees is the lack of transparency of their operation, inadequate mutual informing, and financial issues. The expected positive outcomes of their activities within the network of mental health care providers can be estimated from their mission and objectives (the placement of the mental health area among priority areas in the local community, normalization of mental health, improved acceptance and adaptation to people with mental health disorders, empowerment, improved social inclusion, and mutual support among NGO service users). The criteria for monitoring the quality of NGO operations within the framework of the Social Protection Institute (the indicators) include: service user satisfaction, social network expansion, quality leisure time, the empowerment of service users to take care of themselves, resolution of distress and problems, users' safety, informedness on rights, the participation in decision-making by service users, the reduction of hospitalization numbers, the access to services, promotion and destigmatization, the recognition of the program in the local community (26). NGOs may obtain the NGO quality standard based on ISO 9001, including the following elements: transparency, financial transparency and efficiency, effective internal and external communication, equal treatment of

volunteers and employees, effective management and project implementation, well-thought out building of partnerships and networks (27).

### 1.2 The Aim, Objectives, and Research Question

The aim of the research was to highlight the differences in the understanding of the role of NGOs in the mental health area within the public support network for patients with mental health problems, from the viewpoint of various stakeholders. The findings may help us understand some obstacles in the collaboration between care providers in the support network for people with mental health problems (28–31). The objective of the study was to find out which roles of NGOs are recognized by stakeholders in the support network for people with mental health problems, in order to identify the opportunities for improving the quality of work for people employed in this network and cooperation in developing community care. The basic research question was: 'What are the differences in the understanding of the role of NGOs in the mental health area within the public support network for patients with mental health problems in Slovenia, from the viewpoint of various participants?'

## 2 METHODS

In order to answer the research question, the data from a case study of 56 local communities in two out of nine Slovenian health regions in 2013 and 2014 were used. The cross-sectional study was carried out in phases by combining quantitative and qualitative methods and using specially developed instruments for data collection from various groups of participants: public officials, mental health experts, care providers, and patients and their relatives. Table 1 below presents the research methodology by defining the purposive sample and the methods used.

This article presents the results of the qualitative part of the research, which was based on recognizing people's subjective experience (how they think, what they feel, and how they understand the meaning of various activities for NGOs' operation within the support network for people with depression). We developed an analytical model based on scientific (7) and policy (26, 27) definition of the NGOs' role in mental health. To collect data, semi-structured interviews and focus groups were used. Semi-structured interviews were used in the parts of the research where the sample included individual people. Focus groups were used due to the possibility of a varying number of people being included (from one to more organizations), according to their readiness to take part and the value of cumulative data collection methods (32). Answers to the open survey question about the role of NGOs were also included.

### 2.1 Data Analysis

The NVivo 10 program was used. We transcribed the recorded interviews, focus groups, and answers to the open question in the survey on the role of NGOs for people with mental health problems. The texts were read

**Table 1.** The presentation of the research methodology.

| **The sample** (within the case study of Novo Mesto and Ljubljana health regions) | | **The method used** |
|---|---|---|
| **Public officials** | N=2 (employees from two key ministries) | A semi-structured interview |
| | N=56 (employees of administrative entities in the local communities; one from each local community or according to assigned tasks in the mental health area) | Quantitative method, an online questionnaire via 1KA web interface (including an open survey question) |
| **Mental health experts** | N=5 (experts in the mental health area, not working directly with patients) | A semi-structured interview |
| **Providers** | N=94 (quota sample: 1–3 providers from each health care or social assistance organization, acting in a network of mental health programs and services in Novo Mesto (35,8%) and Ljubljana (64,2%) health regions). 62% are from the health care area, 34% from the social assistance area, and 4% from other areas) | Quantitative method, an online questionnaire via 1KA web interface (including an open survey question) |
| **Service users** | N=82 (men and women with mental health problems, aged 18–70, who accepted the invitation of 4 NGOs or a personal invitation, if they are not NGO members). | Semi-structured interviews and focus groups |

several times and open coded in order to identify the main themes (33, 34). The statements were categorized and anonymised. From both data collection methods, the sources for analysis were mainly statements by various stakeholders highlighting the understanding of NGOs' role. Statements by providers working in NGOs (20%) were analysed separately from statements by providers from other organizations in the support network (80%), and those of the patients, according to whether they were using NGO services (74 patients) or not (8 patients).

### 2.2 Ethical Considerations

All respondents participated in the survey on a voluntary basis, giving an informed consent. Consent for experts and providers taking part in interviews and surveys, respectively, was given by their management; while medical directors, heads of community mental health centres and users' councils agreed for interviews to be carried out with patients at NGOs. Data are presented in a manner that conceals the participants' identities.

## 3 RESULTS

The opinions of various stakeholders on the role of NGOs within the support network for people with depression are presented in Table 2 below.

**Table 2.** A schematic presentation of stakeholders' opinions on the role of NGOs in the mental health area within the support network for people with mental health problems.

| Stakeholders | The summary of opinions on the definition of NGOs' role (categories) |
|---|---|
| **Public officials** for mental health (ministry and local community administration employees) | An innovator and initiator for change, a promoter of health and prevention, an initiator and provider of measures for the quality of life and treatment, an important player for the local community, a user of financial and material resources, the author of a self-evaluation report, the player towards which administrative entities have normatively defined duties, an applicant to tenders. |
| **Experts in the mental health area** | Quality provider, a partner with a specific standing in the support network; the voice of service users and the strongest influencer of people; the contractor with specific (very different) staffing professionals and colleagues. |
| **Service providers at NGOs in the mental health area** | A provider of supplementary services, preventive and community activities, based on the networking and integration of volunteers, offering assistance with no waiting period, a provider of expert individual approach, cooperation in ensuring the continuity of treatment, a provider with above-average ethical potential of providers. |
| **Providers in other organizations within the mental health support network** | A creator of the support network for people with depression and their relatives, the conscience of society, the informer of the public, a provider of proven successful approaches to improving mental health of patients with depression, enables accessibility without stigmatization and reduces stigmatization in the society, the actor whose quality of work depends on the employees, sometimes acting only on paper, their quality varies. |
| **Patients – users of services of NGOs in the mental health area** | Acts towards improved quality of life, resolution of complex issues, a provider of psychosocial and employment rehabilitation, a provider of opportunities for enhancing knowledge, exchanging experiences, social inclusion and quality leisure time activities, an outreach motivator, having the know-how of, and experience in successful methods of working with people with depression, a provider with fast-changing staff members. |
| **Patients – users of other services in the mental health area** | A provider of assistance at home, a provider of free assistance, the organization requires a better promotion of its own work; a provider of assistance only adequate for some patients with depression; organizations the work of which is insufficiently supervised. |

The summary of findings led to the identification of the following NGOs' roles:

- **A provider**: supplementary, voluntary, free services aimed at a particular population group;
- **A supporter**: support for patients with depression and their relatives in terms of advocacy and influence on people;
- **A contractor**: innovative approaches to treatment in the community, psychosocial and employment rehabilitation, help at home, outreach motivation, their activity depends on contractors' relationship and work results, which must be monitored due to the fluctuation of staff;
- **An operator**: linking contractors, patients and experts to improve the quality of life and care for patients with depression by using know-how of, and experience in successful working methods, accessibility without stigmatization, and informing the public to reduce stigmatization;
- **A recipient of support** from administrative entities and local communities in accordance with the normative definition, personal engagement by NGO contractors by participating in tenders, according to a self-evaluating report and public reputation.

There are substantive differences in the understanding of NGOs' role by various interest groups, which are linked to their own involvement in NGO activities. The main differences are seen in their descriptions of the importance of NGO activities for patients. Experts, NGO providers, and NGO service users highlighted the great importance of NGOs for patients, and mostly gave positive descriptions of NGOs' role: 'in NGOs, everything is free, the environment in an NGO is safer than in a bar'. Public administration employees, other providers and patients who are not NGO service users were more critical of the actual importance of NGOs for patients, commenting, for example, that NGOs 'only operate on paper', or that they are a 'provider with frequent personnel changes'. They did not refer to nationally determined criteria for evaluating mental health NGOs' activities in their descriptions and evaluations of the role (26, 27). None of the interest groups showed an understanding of the role of NGOs in their complexity and wholeness (7).

## 4 DISCUSSION

The analysis highlighted a variety of different descriptions forming the picture of the important role of NGOs for patients with mental health problems. There is a characteristic confusion when identifying the roles of various providers. Various interest groups see the role of NGOs in a less generalized way than that cited by Salamon et al. (7). Mainly positive descriptions of the role of NGOs were given by experts and NGO providers. Partly positive and partly critical descriptions were given by municipality employees, other providers and other patients. The range from mainly positive descriptions through neutral to negative ones shows common ground, but also differences between interest groups in understanding the role and importance of NGOs for patients. This gives rise to concerns regarding the potential bias of providers in NGOs and the question of patients' objectivity, them being either users or non-users of NGO services. It is unclear whether these differences are due to the unfamiliarity or actual experience, and whether providers are afraid for 'their territory'. The comparison of the descriptions of stakeholders' roles on one side, with elements of the NGO quality standard, mission and objectives, and criteria for monitoring the quality of NGO operations in the area of mental health on the other side show that stakeholders' descriptions were drawn from their own roles within the mental health support network, and not from the expected role of NGOs in the country.

Previous research shows the importance of understanding the role of NGOs in the country and in the mental health care system (8–10), as well as the practical ways to improve the understanding of individual providers' roles and cooperation. Grayer et al. (11) found a positive response to information on NGOs in the mental health area by patients with mental health disorders and psychosocial problems in medical treatment at the primary health care level. Increased inclusion into NGOs has reduced the number of consultations for these patients due to psychosocial distress.

Inadequate understanding of the role NGOs are playing in the mental health support network can function as an obstacle to the efforts for a connected, harmonized care for patients with mental health problems, including depression, in the community, and for the implementation of patients' right to choose and decide.

Research showed that the sum of stakeholders' understandings of NGOs' role was indeed covering a whole range of their missions, but looking separately, each stakeholder's view was limited in one way or another. We suppose that such differences derive from various separate experiences, maybe even stereotypes, or just ignorance. It is necessary to improve the awareness of stakeholders on all dimensions of NGOs' role within the network of mental health program and service providers, while excluding the presence of stereotypical views (35). Further opportunities to spread information on the role of NGOs for patients include the Support in dealing with depression workshops in community health centres across Slovenia (36). The next opportunity to increase informedness is to upgrade the existing model for publication, entitled Where to seek help for mental

distress (37), which is available for providers and users, with an added description and the expected effects of various support groups. A practical implementation of the NGOs' complementary role should be considered, for example, in terms of support for relatives. NGOs can be an important partner in the area of work with relatives, as medical staff often struggles to meet the needs of relatives and friends when treating patients (38-40).

The findings show that stakeholders mainly see NGOs' role in a positive light; however, they also mention some risks when including a patient into an NGO. The inclusion requires the knowledge of the current status of an NGO in its life cycle, and in the context of the local community support network, as well as the level of service specialization. Mental health problems involve a specific clinical picture of social isolation, various forms of self-destructive behaviour, and the need for intensive motivation at a person's home, which requires a specific approach and immediate action; however, this concern was not at the forefront. The need for NGOs specialized for people with specific mental health problems was confirmed. But it appears that the identified differences have an inhibitory impact on integration processes of NGOs in the community care approach. If qualitative differences between various stakeholders are recognized and taken into account (the understanding of roles and justification of an individual's contribution/needs), there is an opportunity for improved collaboration between providers in the network of programs and services in the area of mental health and the development of community care. NGOs in Slovenia cannot substitute mental health care system; they are, however, an integral part of it, and complement it in a unique and important way.

### 4.1 Limitations

The contribution is an analysis of practice, which needs to be verified by further research. Some findings have been established that may be of value in the development of community care for people with depression. The study limitations are due to the sample selection and cross-sectional design, which to a certain extent, limit the findings' generalizability.

## 5 CONCLUSION

There are many opportunities for developing awareness and understanding of NGOs' role in the network of mental health care providers and services. With improved mutual awareness, constant communication and objective evaluation of all stakeholders' roles in community care, opportunities arise for the collaboration between providers, service users and local communities.

## CONFLICTS OF INTERESTS

There is no financial, personal, or academic conflict of interest.

## FUNDING

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## ETHICAL APPROVAL

Ethical approval for this research was not required. Questions for patients were formulated in such a manner that they did not allow an invasion of privacy or recollection of unpleasant events.

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