WORK (RE)INTEGRATION FOLLOWING A CHRONIC ILLNESS DIAGNOSIS IN ROMANIA: WHAT ROLE DO NONGOVERNMENTAL ORGANIZATIONS PLAY IN THE PROCESS?

ADELA ELENA POPA
ANCA BEJENARU
ANABELLA-MARIA BEJU-ALEMAN
OANA LUP
FELICIA MORÂNDĂU
LIVIA POGAN
IOANA SILISTRARU

A substantial proportion of the workers diagnosed with chronic diseases try to find employment or return to work after treatment. Nongovernmental organizations (NGOs) are key actors in this process of work (re)integration alongside other stakeholders, yet their role has been little studied across countries, and almost not at all in Romania. An in-depth exploration of how NGOs are involved in this process was done through semi-structured interviews with eleven officials of Romanian NGOs. Thematic analysis was employed to understand their views regarding: 1) their role in the process; barriers and facilitators for 2) work (re)integration of chronically ill people and regarding 3) their involvement in the process; 4) collaboration with other stakeholders. The results show NGOs play a significant yet informal and irregular role in supporting these people to find or maintain work, mainly due to the lack of a policy framework. Romanian NGOs face legal, structural, and cultural challenges.

Keywords: *chronic disease; work (re)integration; nongovernmental organizations; employers; health professionals.*

Address of the corresponding authors: Adela Elena **POPA**, "Lucian Blaga" University of Sibiu, Faculty of Social Sciences and Humanities, Romania, adela.popa@ulbsibiu.ro; Anca **BEJENARU**, "Lucian Blaga" University of Sibiu, Faculty of Social Sciences and Humanities, Romania, anca.bejenaru@ulbsibiu.ro; Anabella-Maria **BEJU-ALEMAN**, "Lucian Blaga" University of Sibiu, Faculty of Social Sciences and Humanities, Romania, anabella.beju@ulbsibiu.ro; Oana **LUP**, "Lucian Blaga" University of Sibiu, Faculty of Social Sciences and Humanities, Romania, oana.lup@ulbsibiu.ro; Felicia **MORÂNDĂU**, "Lucian Blaga" University of Sibiu, Faculty of Social Sciences and Humanities, Romania, felicia.morandau@ulbsibiu.ro; Livia **POGAN**, "Lucian Blaga" University of Sibiu, Faculty of Social Sciences and Humanities, Romania, livia.pogan@ulbsibiu.ro; Ioana **SILISTRARU**, Bucharest University, Faculty of Interdisciplinary Studies, Romania, ioana.silistraru@unibuc.ro.

CALITATEA VIEȚII, XXXVII, nr. 1, 2026, pp. 3–27, https://doi.org/10.46841/RCV.2026.01.01

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One feature of the working-age population in Europe and Romania is the increasing prevalence of chronic diseases (CD). The percentage of working-age people (16 to 64 years) with a long-standing illness or health problem grew between 2008 and 2019 with 6.4% in the EU (Eurostat 2024). Chronic diseases impact work participation, hence it is important to make concerted efforts to help people with chronic conditions (PwCD) to enter the labour market (work integration) or to enable PwCD to return to work or remain in work (work reintegration).

Romania has an East European welfare state model (Aidukaite and Navicke 2022), with a long-term underfinanced health system based on social insurance (Popescu *et al.* 2016; Vlădescu *et al*. 2016) which struggles to meet the basic health needs and provides limited resources for rehabilitation. While the prevalence of cardiovascular diseases and cancer is lower compared to other European countries, the mortality rates for these diseases are higher in Romania compared with the EU average (European Commission n.d.). Delayed diagnosis and treatment onset, as well as poor management of the risk factors for CD explain the high mortality rate (European Commission n.d.). This background explains the overall lack of concern on survivorship issues. In addition, the costs of managing CD in the workplace and in general are significant. Studies show higher costs for missed workdays in case of chronic heart failure in Romania compared to other countries (Lorenzovici *et al*. 2022), as well as high costs for managing other CD (European Commission 2023). In this context, the current policy framework on CD and employment is inadequate, as it primarily focuses on compensation, with very few active measures (Popa and Popa 2020).

Nongovernmental organizations (NGOs), such as associations and foundations active in the field of fighting CD, patient groups and associations, and community and voluntary sector organizations do have a role in the work (re)integration of people with chronic diseases (PwCD), mostly in Western countries and in the field of fighting cancer. The role of NGOs in the health sector and in achieving Universal Health Coverage has already been widely acknowledged (Sanadgol *et al*. 2021). Research shows that in developing countries, NGOs already fulfil the expected role of filling gaps in public services and providing support in different domains where the states lack the legal framework, financial resources or institutional capacity to assist people in need (Bebbington *et al*. 2013; Flanigan 2022; Milofsky *et al*. 1998). In Romania, studies show that very few NGOs engaged in fighting cancer have goals related to work participation of cancer survivors (Popa *et al*. 2016). Policy makers do not consider the NGO sector as a formal partner (Popa *et al*. 2021). A similar situation is present in other

low and middle-income countries, despite scientific evidence showing that NGOs should play a significant role in supporting patients with CD (Besançon *et al*. 2022)

Recently, studies have emphasized the importance of understanding multi-stakeholder approaches and the roles of different actors in successful work reintegration. This includes previously overlooked stakeholders such as trade unions and NGOs (Akgüç 2021; Popa *et al*. 2024). Due to the complexity of this issue and its various aspects, involvement from different stakeholders is necessary, including healthcare providers (Magalhães *et al*. 2017), employers (Bosma *et al*. 2021), occupational health services (European Foundation for the Improvement of Living and Working Conditions 2019), government and public health agencies (Souza *et al*. 2021), patients and patient advocacy groups (Schwarz *et al*. 2024) or by a combination of those actors.

NGOs have been anecdotally acknowledged to play a significant role in a country's progress towards work reintegration of PwCD, yet scientific evidence remains rather sporadic and scarce, leaving this presumably fertile ground largely unexplored. More specifically, to our knowledge, there is very limited literature on how NGO representatives understand their involvement in enabling the work (re)integration of the PwCD. In this context, this paper sets out to explore the perspectives of Romanian NGO representatives, based on their experience, regarding this involvement and aims to find a response to four research questions: 1) How do NGOs see their current and potential role in work (re)integration of PwCD? 2) What are the barriers and facilitators faced by PwCD in relation to work (re)integration? 3) What are the barriers and facilitators faced by NGOs in helping PwCD to (return to) work? 4) What forms of collaboration of NGOs and other actors are in place, and they would suggest to be in the future? By doing this, the present paper fills the missing link, which is how NGOs view their current and potential contribution to increasing work participation of people who have a diagnosis of CD but are still able to work. It is noteworthy that this exploration is done in the context of a country with a limited policy framework for rehabilitation and return to work (Belin *et al*. 2016) and scarce involvement of the civil sector in survivorship and rehabilitation issues (Popa *et al*. 2016) thus, the results can be relevant to other countries with a similar profile, *e.g*. most of the Central and Eastern European countries.

REVIEW OF LITERATURE

Regarding the actual involvement of NGOs, the existing literature shows consistent engagement in work reintegration mostly for cancer survivors, while in the case of other CD, fewer initiatives are available. Notably, in France, all return-to-work interventions for patients with breast cancer appear to be led by NGOs or social security in hospitals (Martin *et al*. 2022). Moreover, reported results from the grey literature indicate many available return-to-work interventions of NGOs in

Europe covering consultancy services and information provision (European Agency for Safety and Health at Work 2018), advocacy efforts to reduce stigma and financial discrimination (Youth Cancer Europe 2018) and financial support to advance the research on the experience of returning to employment following a cancer diagnosis (Connolly *et al*. 2021).

Two prominent examples of NGO involvement in work reintegration are Macmillan Cancer Support in the United Kingdom and the Clubhouse model for people with mental conditions. Macmillan Cancer Support provides support services and advocacy for employment and vocational rehabilitation based on the patient's needs (Gail *et al*. 2012; Wells *et al*. 2013). The Clubhouse model, non-profit organizations operating as community centres where patients and staff engage in decision-making and governance in order to achieve transitional employment for people with mental conditions, has gained a lot of interest in recent years (Tanaka *et al*. 2021).

Despite the extensive studies of barriers to work reintegration for people with specific CD as understood by different stakeholders (Ayala *et al*. 2022; Corbière *et al*. 2017; Dekkers-Sánchez *et al*. 2013; Grant *et al*. 2019; So *et al*. 2022; Sturm *et al*. 2020; Zomkowski *et al*. 2019), very few studies offer the perspectives of NGO representatives on such barriers. As reflected in our research questions, there are two strands of literature on understanding the barriers: the barriers hampering the work reintegration of PwCD and barriers hindering NGOs efforts to provide support for such people. In the first category, NGOs working in this field at the European level identified obstacles such as lack of awareness, stigmatization, discrimination, inadequate resources, poor collaboration, and limited access to healthcare programs (Vlachou *et al*. 2018). Another study shows that the barriers to work reintegration identified by NGOs are similar to those identified by other stakeholders and can be grouped into several categories: inadequate or limited policy frameworks for RTW; challenges in applying existing legislation due to its complexity, fragmentation, or insufficient funding; limited resources for providing workplace accommodations for people with different types of CD, particularly in small companies; stigmatization and discrimination; and difficulties associated with long periods of absence from work (Popa *et al*. 2023). In the second category, Baxter and Fancourt (2020) detail the difficulties with securing funding in the case of community and voluntary sector associations working with patients with mental illness. The challenge to obtain adequate funding negatively impacted the training and supervision of staff and the long-term delivery of services.

There is a wealth of literature on the factors facilitating work reintegration for PwCD (De Vries *et al*. 2018; Greidanus *et al*. 2018; Haafkens *et al*. 2011). However, very few studies focus on how NGOs view the two categories of facilitators: first, helping PwCD and second, assisting NGOs in offering support. In the first category, a study on patients with stroke highlighted the role of vocational programmes in work reintegration of this category (Bin Zainal *et al*. 2020). In the

second category, NGO officials mentioned the strong partnerships with other stakeholders involved in this effort, particularly health professionals. Additionally, they emphasized the unique role of NGOs as organizations that provide a safe space for their clients and can offer innovative and creative types of support (Baxter and Fancourt 2020).

Collaboration refers to formal and informal channels of working together with other actors and the coordinating mechanisms that are in place. Effective collaboration was deemed as highly important for the success of work reintegration process in case of PwCD (Ladekjær Larsen *et al*. 2022; Svärd *et al*. 2024). The situation varies across countries regarding how formal the channels of collaboration are and how many actors are significantly involved in the process. Nordic and Western European countries which have a more comprehensive system of rehabilitation and return to work have well-established and clear paths of collaboration, while in the rest of the countries, there is a prominence of informal ways to cooperate (Belin *et al*. 2016; Popa *et al*. 2023). It has been shown that collaboration must also be initiated between actors from different sectors, for example, the healthcare sector and the social security sector (Ladekjær Larsen *et al*. 2022). Studies also show the importance of timing in initiating collaboration. Early-stage collaboration between occupational physicians and employment services increased the success of return-to-work interventions (Bassele *et al*. 2023). Emphasis is also placed on how to collaborate, such as through shared decision-making (Ristimäki *et al*. 2020).

In summary, although the role of NGOs in reintegrating PwCD into the workforce, along with other stakeholders, has been recognized in some countries, in countries lacking a comprehensive framework for involving all relevant actors, this role has been understudied so far. Additionally, the involvement of NGOs in work (re)integration has mainly been studied in relation to cancer and less so in relation to other CD. The perspectives of NGO representatives on the barriers, facilitator factors and collaboration between actors in this process require further investigation.

RESEARCH DESIGN AND METHODS

Research design and ethics

This study is part of a larger project[1] in which we used an ecosystemic perspective in order to understand the role of various stakeholders in the return-to-work process for individuals with chronic diseases. We explored the interactions between external factors, such as employers, healthcare professionals, support

[1] The project was entitled "The challenges of returning to work after chronic illness in Romania: barriers, facilitators and collaboration of stakeholders" (RTW-CI), code PN-III-P4-ID-PCE-2020-1384, and was funded by CNCS-UEFISCDI.

organizations and policy-making actors, that influence the reintegration of these individuals into the workforce. This approach allowed us to identify the conditions and mechanisms that facilitate or hinder the success of return-to-work, highlighting the complexity of relationships among the various actors involved.

To understand how NGO representatives see their involvement in work (re)integration of PwCD, we employed an exploratory qualitative research design using semi-structured interviews. The research was approved by the Ethics Committee in Scientific Research (approval number 12/17.02.2022).

Participants and sample

We used purposive sampling to select representatives from NGOs in Romania based on the following eligibility criteria: (1) working in the field of fighting various CD; (2) engaging not only in charity but also in advocacy for survivorship and employment issues of individuals with CD; (3) having done programmes at the national level; (4) being based in various geographic areas in Romania. To ensure a broader coverage and a diverse sample, we employed a variety of approaches for identifying the potential respondents. Potential respondents were identified via a snowball approach, through national and personal networks, by reaching out to collaborators from previous projects, or by searching NGO websites and social media. We found that there are few associations and foundations in Romania focused on advocating for employment issues following CD. As a result, we identified 14 potential respondents which checked the eligibility criteria. After creating this database, we developed a protocol for contacting them via email and telephone. Three of those contacted either did not respond or declined participation, perhaps due to limited awareness of work (re)integration issues or lack of familiarity with such studies.

Our final sample included 11 respondents affiliated with nationally recognized associations or foundations. The average age was 49 (Table no. 1). A large part of NGOs was based in Bucharest, the capital of Romania. Most respondents were presidents of their NGOs. Four of the NGOs specialised in cancer, but other major diseases were also represented in the sample. One NGO also deals with secondary disabilities, i.e. disabilities resulting from a CD.

Table no. 1

Participants' characteristics

Participants' characteristics	**Number of participants (n=11)**
Gender	Female 7 Male 4
Age	Average: 49 Range: 23-70

City	Bucharest: 6 Brasov: 1 Cluj-Napoca: 1 Giurgiu: 1 Ploiesti: 1 Zalau: 1
Role of respondent in the NGO	President: 8 Executive director: 1 Vice-president: 1 Vocational counsellor: 1
Disease on which NGO is specialised	Cancer: 4 Mental health: 2 Diabetes: 1 Haemophilia: 1 Hepatitis: 1 HIV/AIDS: 1 Rare diseases and disability: 1

Data collection

The interviews took place between March and November 2022 using a semi-structured format. AP, AB, and FM developed and pilot-tested the interview guideline. The interview covered topics such as the role of NGOs in work (re)integration, the barriers to workers' integration, the challenges faced by NGOs, the factors that facilitate the (re)integration of patients into work, but also the factors helping NGOs to offer support and the collaboration with other stakeholders. Two experienced researchers (FM and IS) conducted the interviews *via* the Zoom platform, as respondents were located in various cities. None of the researchers involved in developing and conducting the interviews had connections or financial interests with the NGOs included in our study. The researchers have extensive experience in conducting semi-structured interviews with individuals with health conditions, as well as the stakeholders who influence their return to work, experience gained in previous projects on this topic. Acknowledging the potential impact of researcher positionality on both data collection and analysis, the team adopted a reflexive approach throughout the study. This involved continuous self-reflection to identify and mitigate any biases or assumptions that could have influenced data interpretation. Regular team discussions were held to ensure multiple perspectives were integrated, thereby reducing subjectivity and enhancing the objectivity and rigor of the analysis.

All respondents signed a written consent form before the interview. Participants were asked to complete a short questionnaire regarding gender, age, position in the organisation and NGO type and scope of activities. The discussions were audio recorded, and the interviews lasted 71 minutes on average. Identifying

information was removed, and unique codes were assigned to every interview, ensuring anonymity in every stage of the transcription and analysis. Transcriptions of the interviews were done verbatim.

Data analysis

Thematic content analysis (Saunders *et al*. 2023) was performed using NVivo14. In the first stage, all researchers thoroughly read the transcripts. The second stage was devoted to coding which was largely collaborative, with all researchers contributing to the process. A mix of deductive and inductive approaches was used for developing the codebook. Thus, the development of the first and second-order themes was mainly theory-driven, informed by the literature review and the research questions, and it was carried out by the principal investigator (AP). For the third-order themes, an inductive approach was used. After a preliminary coding of several interviews, the resulting codebook was discussed with all investigators.

Subsequently, all transcripts were coded based on the final codebook. Each interview was coded by two members of the research team to ensure code reliability. Periodic meetings were held to discuss any issues and divergences between the coders. In the final stage, all researchers independently drafted themes, which were compared during a meeting, to develop the final list of themes.

RESULTS

During the analysis, 24 third-order themes emerged within the four main themes and the nine second-order themes (Table no. 2). Some themes have a twofold aspect, as respondents discuss the topic in relation to both the workers and the NGO itself.

Table no. 2

Themes emerged from the data

A. Roles of the NGO in relation to work (re)integration
1. Roles in relation to workers
2. Roles in relation to the Government, authorities and civil society
B. Obstacles in relation to work (re)integration
1. Obstacles concerning the workers' integration, as seen by the NGOs
a. Related to the legal framework
b. Related to health professionals and the medical system

c. Related to employers

d. Coming from social attitudes or lack of social action

e. Related to the PwCD themselves

2. Obstacles faced by NGO when helping pts to be integrated in work

a. Low funding and resources coupled with high bureaucracy

b. Lack of collaboration with other actors

c. Pandemic as an obstacle

C. Facilitators in relation to work (re)integration

1. Facilitator factors helping PwCD to be (re)integrated in work, as seen by the NGO representatives

a. Help from health and care professionals

b. Family, caregivers and community

c. Legal counselling

d. Other facilitators

2. Facilitator factors helping NGOs

a. Having constant and predictable funding and resources

b. Collaborators

c. Adequate legal framework

3. Who should offer facilitators, and limitations of current facilitators

a. The state and statutory services

b. The workers themselves

c. Limitations of current facilitators

D. Collaboration with other stakeholders

1. Collaboration with various actors

a. Healthcare professionals and nurses

b. Employers

c. State institutions

d. Other actors

2. Challenges in collaboration

a. With the healthcare professionals

b. With the employers

A. Role of the NGO in relation to the professional work integration of persons with chronic diseases

1. Roles in relation to workers

The focus of this theme was on the current role NGOs play in helping workers with CD. The organizations are involved in various ways, such as helping workers find jobs, providing legal and medical education and counselling, offering psychological support, creating communities for patients, involving patients in organizational activities, and raising awareness on the topic. The NGO representatives often use personal connections to help workers find jobs due to the absence of formal channels of job finding. One respondent indicated that legally compelling a company to hire an employee with a certain condition could be detrimental to the worker.

> *"Yes, we could appeal to the legal rights of the workers with chronic diseases to be hired or accommodated into the workplace, but it would not be to the patient's advantage to do so. We could win the case when the person for whom we are legally intervening is a healthy person. But when we talk about a chronic patient who arrives in a place where he is not wanted and not well received, the result is that the person would have to face two burdens. The fact that they're working in a hostile environment consumes them more than the disease itself or as much as the disease. (NGO-6)"*

Regarding legal education and counselling, NGOs offer support by educating and counselling patients on legal matters and navigating bureaucratic processes. For example, patients are informed that occupational physicians must write on the fit note only "chronic disease" and not the explicit name of the disease (*e.g.*, hepatitis). Yet, few workers benefit from this type of counselling because NGOs' resources are limited. Their efforts include offering medical education on CD in companies, delivering medical education programmes, or educating the workers' caregivers.

Providing practical and psychological support is a significant part of their role. Finding financial resources to help workers with their physical needs (*e.g.*, knee and hip prostheses) can be an indirect way to help them find jobs. On the psychological side, one example is an annual event organised by an NGO in the field of Haemophilia, that brings together patients, caregivers, and healthcare professionals for socializing and psychological support. NGOs also create support groups for patients with the same condition.

Involving clients in NGO activities is highly valued as they can effectively lobby using their own experience regarding the disease, and such activities contribute to an increase in the clients' self-esteem, thus helping them to transcend their victim status.

> *"Being part of this event nourished them inside, not only because they were useful but because they transformed the energy of that disease into something creative for themselves and for others, which is a great gain. That is, they have gone from being victims, from waiting to receive compassion or care to offering understanding and wisdom to others." (NGO-6)*

2. Roles in relation to the Government, authorities and civil society

Under this theme, the roles mentioned include involvement in policy change, being a link between the workers and public authorities, acting as a substitute for the state and physicians (*e.g.* when providing medical education), and involvement in prevention.

> *"To propose or modify the smallest article in a law, sometimes you can lobby and work for years, which means countless meetings, countless phone calls, and countless discussions and resources that you allocate in that direction, sometimes to the detriment of the organization's beneficiaries." (NGO-1)*

One noteworthy role described here was that of "mirroring" the patients' situation, in that they cannot do much in some situations, so they witness it and become spokesperson on public channels.

B. Obstacles in relation to work (re)integration

The accounts in this category were much more abundant than in other categories. Obstacles were discussed both in relation to PwCD integration and to the barriers organizations face when trying to help such workers.

1. Obstacles concerning the workers' integration, as seen by the NGOs officials

Within the first theme, most of the obstacles pertained to the legal system and framework, followed by obstacles related to the medical system and employers.

Less mentioned were the barriers generated by social attitudes or lack of social action, as well as barriers coming from workers themselves.

a. Obstacles related to the legal framework

Respondents are concerned about the lack of a legal framework to regulate the professional reintegration of PwCD. This includes the absence of a National Cancer Control Plan, a national strategy for mental health, a national registry of haemophiliac patients, and a legal framework for providing benefits to aid the reintegration for both employees and employers. These gaps hinder support for PwCD to stay in the labour market and prevent the government from having a comprehensive involvement of relevant actors and planning sustainable funding accordingly.

The cost of physical rehabilitation, limited state coverage, and long waiting times are obstacles which indirectly impact work (re)integration. The disregard of certain legal rights and the lack of expertise and vision in public authorities are also significant barriers.

b. Obstacles related to health professionals and the medical system

Many of the obstacles in this theme pertain to occupational physicians, and problems are expressed in conflicting ways from one respondent to another. Thus, some respondents consider that not having the disease mentioned on the fit note might be an obstacle in reintegration because it poses some risks for the worker, a statement that contrasts with the one mentioned above about the necessity of educating occupational physicians not to write the name of the disease on the fit note. Examples of role ambiguities of occupational physicians, false claims about specific diseases, and in some cases, law violations were clearly and lucidly stated.

> *"One of the difficulties I see is the vagueness of the legislation on occupational medicine. It is not very clear what the occupational doctor should do. The heads of the occupational medicine commissions at the Ministry of Health see occupational medicine as having mostly a preventive role, protecting the employee and intervening especially in the case of occupational diseases. But then there are the doctors in the territory who see occupational medicine as a protection for employers to hire staff with health problems that would make their work difficult. Also, we have many situations in which the occupational physician, although he has no legal basis, gives an 'unfit' assessment to a person infected with HIV, although there is no activity sector in which a person with HIV is unfit." (NGO-7)*

> *"The occupational physician did not want to put the 'fit' assessment on the fit-note because he claimed that the patient with hepatitis B could pass on the disease, although his viremia was undetectable."(NGO-1)*

Participants recognized the difficulty of accessing medical support and preventive care due to excessive paperwork, insufficient personnel, and lack of equipment. For instance, in one county, there was no mammography equipment.

When the NGO obtained it, the specialist doctor who could operate the equipment had already left the hospital.

c. Obstacles related to employers

Employers are reticent, and some of them actively oppose the hiring or reintegration of persons with CD or secondary disabilities. Thus, in some cases, they refuse to dialogue with NGO officials because they wish to avoid potential complications. Some employers go even further and ask for unnecessary psychological tests if they interview a person with special needs, and usually, the workers fail such tests.

> *"Many times, we do not mention to employers that the person has a disability because they refuse to meet him from the start. If they find out that they have a disability or they see something at the interview, they ask for psychological testing; even if the person has to wash dishes, broom, or take out garbage, they ask for a psychological test, and usually the test is failed." (NGO-8)*

d. Obstacles related to social attitudes and lack of social action

Accounts of discrimination, marginalization, stigmatization or prejudice were provided also in relation with other actors. Examples included a school principal refusing access to NGO representatives, claiming there is no HIV in the school, and a teacher with a child with leukaemia being isolated by her colleagues because of her child's illness.

> *"Yes, the law does not prohibit the employment of people with HIV, on the contrary, but in practice the reality is different. So even when the law is supportive, people can do harm." (NGO-6)*

Some respondents emphasized the potential negative influence co-workers can have in the adjustment period after the worker resumes work.

> *"Then there is the social pressure from coworkers: they look at their colleague (because usually they know she was sick), and everyone is curious to analyse her, to see if she has breasts or doesn't have breasts anymore, to see how she looks and clearly this puts pressure on her and makes her behave in a certain way." (NGO-5)*

Other respondents complained about the lack of sustainable social action towards the facilitation of work participation of PwCD, besides disparate and fragmented initiatives.

> *"Everyone knows the elephant in the room [a.n., the work integration of PwCD], but the actors involved in offering support and the governmental actors never stayed at the same table in a sustainable way to find solutions for this problem."* (NGO-4)

e. Obstacles related to the PwCD themselves

Some barriers are related to the unfulfilled needs of PwCD (not receiving treatment during the pandemic, no funds for their care). Also, NGO officials acknowledge that workers with intellectual disabilities and mental issues are difficult to work with, as they need a lot of counselling and training.

2. Obstacles faced by NGOs when helping workers to be integrated into work

a. Low funding and resources coupled with high bureaucracy

The main barriers in this theme were having no funds for short or long periods of time, missing legal benefits due to not being a public utility organization, and not being able to afford volunteers.

> *"We could not afford to pay the rent for a space in which to function, and for a period of time, we could not pay the personnel also… We could not afford to have volunteers because we had no funds to train them and to offer them the small benefits which are provisioned by the volunteer law." (NGO-1)*

b. Lack of collaboration with other actors

Part of the NGOs mentioned the lack of formal collaboration with employers and employer associations, as well as with state institutions such as ministries or agencies. The main reason invoked is the lack of formal channels of collaboration. Hence, NGO representatives who are more proactive can build a network of collaboration, while others fail to do this.

> *"I don't collaborate with employers; I only collaborate with my friends who are employers." (NGO-6)*

c. Pandemic as an obstacle

As expected, the pandemic greatly affected NGOs, and as a result, they had to reinvent themselves, move some activities online, and drop the ones that couldn't be done online.

C. Facilitators in relation to work (re)integration

1. Facilitator factors helping workers to be (re)integrated in work, as seen by the NGO representatives

a. Help from health and care professionals

The availability and generosity of some doctors, who volunteered with an NGO to provide medical education to breast cancer patients in remote rural areas, in an effort to reduce the number of cases seeking medical advice too late, was cited as a facilitating factor in this initiative. This was in addition to the psychological support provided both within the organization and within hospitals.

b. Family, caregivers and community

Many respondents emphasized the importance of family, caregivers, and community support in general and for work integration. PwCDs with a strong support network are in a much better situation than those who are alone. The facilitative role of residential services was also mentioned.

c. Legal counselling

Legal counselling must exist for workers who face employment difficulties, but participants also stress that legal counsellors must be passionate and persistent because some facilitations are hard to obtain even when they represent a worker's rights.

> *"Only the involvement and effective communication of the legal counsellor can change the situation in some cases. In the case of the breast cancer patient, the legal counsellor presented all the aspects, especially the health and family-related aspects, because she was the only provider of the family with five children, so he tried to get the employer to be empathic and yet she was not hired." (NGO-10)*

d. Other facilitators

Several factors are mentioned here, such as changing the social perception regarding CD through education from an early age, facilitating access to professional reconversion, or educating health professionals as sometimes their knowledge of specific diseases is not up to date if they are not specialists.

2. Facilitator factors helping NGOs

a. Having constant and predictable funding and resources

According to our respondents, funding is the most crucial facilitator. While some measures are available, they are not sustainable solutions and can only be seen as emergency solutions. For instance, the '3.5%' measure, which allows individuals to annually redirect 3.5% of their income tax to an NGO, generates minimal funds for NGOs. Additionally, very few NGOs receive financial support from foreign organizations, only the ones that were originally established as part of these organizations. Securing national and international funding through competition is challenging for most NGOs. As a consequence, most NGOs struggle with not having basic resources, such as a proper space where to function.

b. Collaborators

One significant facilitator factor for NGOs is the collaborators they work with. Two main categories are frequently mentioned: volunteers and doctors. NGOs often collaborate closely with doctors, who may be employed by the NGO, act as volunteers, or be part of local health services. As an exception, one NGO mentioned a female politician who volunteered her spare time to educate patients in remote areas about cancer.

c. Adequate legal framework

NGOs need a legal framework that would support their prevention activities. One example given was the need for a policy framework allowing for comprehensive breast cancer screening for women of all ages.

"I had a discussion with the Minister of Health at the time, and I explained to him, "Look, other countries have such screening programs, these are the conditions, etc." Initially, he said it couldn't be done, and finally, he felt pressured and shrugged, "It's not on our agenda." So the screening was not a priority for that minister." (NGO-6)

3. Who should offer facilitators, and limitations of current facilitators

a. The state and statutory services

Several actors were mentioned as potential sources of facilitating the process of work integration after CD such as the state, county and local public authorities, the unemployment service, the town halls or any other service with civil servants (social workers, psychologists) capable of identifying and addressing labour reintegration problems. Many NGO officials discussed the counselling and psychological services that should be provided or at least partially covered by the state.

b. The workers themselves

In some respondents' view, the PwCD can create a great impact and can enable the process as they can make effective advocacy based on their own experience. Working-age PwCD who have a personal and meaningful story of work reintegration can educate other patients either on personal networks, or through an NGO, or at a bigger scale, through (social) media channels.

"I don't think it depends on the ministry, but on people with chronic illness who have gone through a situation of returning to work. And I also think it would be necessary to organize a large project carried out by the federation together with all the associations and to have a very large campaign on social media on this topic." (NGO-3)

c. Limitations of current facilitators

There are several factors in place that can facilitate the process, but many of them have limitations. One limitation, according to the respondents, is that employers cannot be forced by the law to integrate PwCD, or the lack of sanctions in case they do not provide reasonable accommodations. Another limitation is the fact that the law exists but is not enforced.

D. Collaboration with other stakeholders

1. Collaboration with various actors

a. Healthcare professionals and nurses

The most frequent and intense collaboration is with healthcare professionals, especially specialist physicians who are often volunteers in NGO activities. Good cooperation also takes place with psychologists and trained nurses. However,

respondents' accounts depict a different image regarding the collaboration with occupational physicians (OccP). Some describe them as reserved in their efforts and open to facilitating work reintegration, while others say they sometimes disregard the recommendations from specialist physicians and associations regarding this process.

b. Employers

If the relationship with healthcare professionals is appreciated as being generally good, not the same can be said about employers with whom the collaboration is rather low and difficult. NGO officials say employers fear of hiring PwCD or disabilities resulted from the CD, therefore they reject part of the initiatives from associations, or they have difficulties in engaging in collaboration.

> *"Indeed, employers are afraid too, because they do not know details about this disease. That's why we always try to educate them. To the association's clients who are looking for a job and go to interviews, we always say: «Talk to the employers you go to, explain to them what diabetes means, what can happen when an employee has this disease, what are the signs of hypoglycemia, what they can do in this case, etc.» We have to make them understand that it is possible to work with this disease." (NGO-3)*

> *"We went from employer to employer and educated them on viral hepatitis and hepatitis B. We collaborated more before the pandemic, now the cooperation is not as good as before." (NGO-1)*

Not many officials speak about satisfactory or good collaboration with employers. One NGO has developed a small network of employers over the years with whom they work, while another NGO always collaborates with the same employers, as their willingness to hire workers with health problems has remained consistent over the years.

> *"We have created a mini-network of employers who are more open to hire people with mental issues and we keep in touch with them. We have created this network from scratch, we found employers on the Internet, called them, and they said yes, and since then, we have strengthened our relationship.*" (NGO-8)

c. State institutions

The NGOs collaborated with various ministries of health on national programs. They established connections with the National Health Insurance House, which became more open to communication during the pandemic. They also held meetings with local authorities for people with disabilities, where they involved individuals with disabilities to ask questions and advocate for their rights. Additionally, they worked with the Ombudsman on a few cases.

d. Other actors

In this category, respondents mentioned professional associations (*e.g.*, the College of Physicians), and working with other associations and federations when they initiated cooperation.

2. Challenges in collaboration

a. With the healthcare professionals

It appears that the primary challenge lies in the limited time available for collaborating with specialist physicians. Despite their time constraints, some collaboration does occur, mainly involving medical education, preventive measures, and counselling. In addition, one association holds regular meetings with doctors to discuss specific cases. The collaboration with OccP is even more difficult because they do not initiate contact with NGOs. In the limited collaboration that is taking place, they are perceived as less empathetic and reserved.

> *"Regarding occupational medicine, we have never been called to participate in an event organized by occupational physicians, like a conference or anything similar. I don't know if other NGOs have been called. It would have been good to be able to talk face to face with them, and tell them how we see the problem of people with chronic diseases, and maybe understand each other better. I can say that it is a collaboration towards zero." (NGO-1)*

b. With the employers

Associations often have to deal with employers' refusal to work with them. In one case, the employer refused the free testing for diabetes of more than 100 employees because they could do it on their own at their general practitioner clinic. In another case, employers refused the collaboration, stating that they have an occupational physician who covers all the medical aspects of the organization.

DISCUSSION

This study explored the involvement of NGOs in helping PwCD (re)integrate into the workforce, the barriers and facilitators encountered by both the workers and the NGOs in providing support, as well as the collaboration with other stakeholders. The key findings indicate that NGOs do play a significant role in supporting PwCD to find or maintain work at various levels, yet their involvement is informal and irregular, mainly due to the lack of a policy framework to regulate their role. Despite being a stakeholder capable of fighting or offering consistent support regarding the obstacles faced by PwCD, NGOs face significant legal, structural and cultural challenges in their activity. While NGOs generally

collaborate well with healthcare professionals, their relationship with employers is more challenging. We will detail these findings below.

First, NGOs play a significant role in integrating PwCD into the workforce, operating at both micro and macro levels, yet the first level is more prominent in their activity. At the micro or individual level, NGOs provide various forms of support that go beyond simply helping individuals find jobs or reintegrating them into the workforce. Even when practical support cannot be offered, they 'mirror' or witness the worker's situation and, in some cases, bring attention to it publicly to raise awareness. Thus, even when they feel there is not much to be done, they can still talk publicly about the patients' situation, which they have called 'to mirror the patient story'. While most NGO activities occur at the micro level, they also work at the macro or community level by advocating for policy changes or prevention or by acting as a link between the worker and public authorities. Our research aligns with findings from other studies, indicating that in countries where the state is perceived as the primary driver of policy development, NGOs play a limited role in planning and implementing RTW policies (Popa *et al*. 2023).

It is also important to note that NGOs' roles in assisting PwCD in returning to work or finding a job are diverse but inconsistent. This inconsistency is mainly due to the lack of a comprehensive policy plan regulating these processes. Therefore, the support provided by NGOs varies depending on their specific resources and capabilities, resulting in a variable level of assistance. Finally, it is noteworthy that even when official channels are available, reliance on informality is preferred. This reflects both a cultural preference and a perceived challenge with formal procedures. This finding is consistent with previous studies showing a varying degree in the formalisation and comprehensiveness of the return to work practices (Lemieux *et al*. 2011; Young and Choi 2016).

Second, barriers are extensively discussed, highlighting their importance to NGOs, and all of them can be understood as facilitators, if reversed. Similar to other articles, the present study shows consistent obstacles are invoked regarding the lack of a proper legal framework to regulate the work integration process (Vlachou *et al*. 2018), the inconsistent or insufficient support from health professionals (Tamminga *et al*. 2012), barriers pertaining to the workplace environment (Lemieux *et al*. 2011) or the personal features of the worker (Dekkers-Sánchez *et al*. 2013). Regarding the NGOs' activity, barriers at the structural level are related to the scarcity of resources to support the work integration of PwCD and their access to prevention and other necessary services, as well as the lack of a specific legal framework and high bureaucracy. At the cultural level, employer reluctance, social prejudices, and discriminatory attitudes towards PwCD are mentioned.

Third, the collaboration with other stakeholders, particularly specialist physicians and psychologists, is perceived as satisfactory, whereas the relationship with occupational physicians tends to be less satisfactory. While some studies have

shown that employers may have negative attitudes towards reintegrating their employees (Fu 2008; Raque-Bogdan *et al*. 2015; Tamminga *et al*. 2012), there have been, to our knowledge, no studies indicating problematic collaboration between NGOs' and employers. Thus, one original finding is the employers' reserved or even upfront discriminatory attitude, which is mentioned by NGOs as a major obstacle in collaboration.

STRENGTHS AND LIMITATIONS

To our knowledge, this is the first study in Romania to explore the role of NGOs in the work reintegration of people with a diagnosis of chronic illness. The perspective of NGOs is valuable, as they play a crucial role in helping individuals adapt to difficult situations and are innovative in their approaches. We gathered insights from NGOs with diverse profiles and varying experiences in the field. Unlike previous studies, focusing on NGOs' views alone and not in conjunction with other specialists, is another strength of this study. The results offer a comprehensive understanding of the main challenges NGOs involved in this field face. Another strength is that, in a context where awareness about work (re)integration challenges is low, our study has encouraged NGO representatives to reflect on this topic and become more motivated to be further involved. However, a limitation of the study is the relatively small number of NGOs involved, which limits the transferability of the conclusions and the relevance of the research to countries with similar health systems and policies.

IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH

Based on these findings, it is important to consider an integrated and coordinated national legal framework to clearly regulate the role of NGOs in the work (re)integration of PwCD. This framework could significantly contribute to harnessing the potential of this stakeholder in this process and could be a means to secure constant and predictable funding. Currently, NGOs' involvement is informal and not fully valued. Providing NGOs' with a formal role in policy could improve the effectiveness of their efforts by professionalizing their services and fostering increased collaboration across different sectors. More studies are needed to explore the involvement of NGOs along with the other stakeholders shaping this process, and how this involvement varies across countries with different policy frameworks for work reintegration and varying levels of resources.

Acknowledgements

This work was supported by: (1) a grant of the Ministry of Research, Innovation and Digitization, CNCS/CCCDl - UEFISCDI, project number PN-IV-

P8-8.1-PRE-HE-ORG-2024-0233, within PNCDI IV, and (2) the project 'The challenges of returning to work after chronic illness in Romania: barriers, facilitators and collaboration of stakeholders' (RTW-CI), code PN-III-P4-ID-PCE-2020-1384, with funding from (CNCS-UEFISCDI).

AI Use Statement

"No artificial intelligence (AI) tool was used at any stage or in any form during the preparation of the manuscript."

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Un număr mare de angajați diagnosticați cu o boală cronică încearcă să își găsească un loc de muncă, sau să revină la muncă după tratament. Organizațiile Nonguvernamentale (ONG-urile) sunt actori – cheie în acest proces al (re)integrării în muncă alături de alți stakeholderi, deși rolul lor a fost puțin studiat în diferite țări și aproape deloc în România. O explorare în profunzime a felului în care ONG-urile sunt implicate în proces a fost realizată prin interviuri semi-structurate cu 11 reprezentanți ai unor ONG-uri din România. A fost folosită analiza tematică pentru a înțelege perspectivele acestora cu privire la: 1) rolul lor în proces; bariere și facilitatori pentru 2) (re)integrarea în muncă a persoanelor cu afecțiuni cornice și legate de 3) implicarea în proces; 4) colaborarea cu alți stakeholderi. Rezultatele arată că ONG-urile se confruntă cu provocări legale, structural și culturale.

***Cuvinte-cheie**: boală cronică; (re)integrarea în muncă; organizații nonguvernamentale; angajatori; specialiști în domeniul sănătății.*

Received: 22.09.2025 *Accepted: 12.11.2025*