

# THE SOCIAL INCLUSION OF HIV-AFFECTED PERSONS – A CHALLENGE FOR TODAY'S SOCIETY

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**Abstract:** *The human immunodeficiency virus (HIV) infection continues to be one of the most controversial and stigmatizing diseases in history. Since the discovery of HIV, the infection has acquired medical and social dimensions, stigma and isolation tendency being some of the most obvious effects felt socially. The evolution of HIV infection since the discovery of the first case in 1959 in the Leopoldville region, the Belgian Congo (now Kinshasa, Democratic Republic of Congo), has reached pandemic dimensions as in 2021 over 37.7 million cases were reported. In Romania, among other problems inherited from the old communist system, during the years 1986-1992 we witnessed a negative record in terms of the number of HIV-infected children, taking into account that about half of the total number of cases recorded at that time were in our country, with over 1000 confirmed cases of paediatric HIV / AIDS out of a European total of 2000 cases. The aim of the research is to identify the manner in which social protection measures in Romania promote social inclusion and combat discrimination against people affected by HIV-AIDS in the Valea-Jiului micro-region. The data collection was performed by means of a questionnaire-based sociological survey. Discrimination in relation to HIV infection continues to be present in the medical-social field, insufficient information about the routes of transmission make HIV-positive people unwanted by society. The interventions of the Romanian state in the case of persons affected by HIV-AIDS are limited in the form of disability or, as the case may be, pension allowances, other active measures of social inclusion being absent.*

**Keywords:** HIV; Social Inclusion; Stigma; Disability.

## 1. Literature review

### 1.1 Conceptual delimitations

The Human Immunodeficiency Virus (HIV) is a highly virulent pathogen that attacks the cells of the immune system by multiplying inside them, then destroying the same. The main target of the human immunodeficiency virus is represented by the T4 cells (helper) on whose surface there is a protein called CD4.

Roger Pebody (2021) exemplifies that HIV-1 was first discovered and is the most widespread type in the world, while HIV-2 differs in its genetic structure from HIV-1 by 55%.

HIV-2 is most common in West Africa and is becoming more common in India, although the number is still relatively low. A reduced number of cases have also been reported in Portugal, France, other European countries, including the United Kingdom and the Americas, mostly in individuals of West African descent or their sexual partners.

Due to the genetic difference, HIV-1 and HIV-2 antigens are distinct enough that if a diagnostic test is developed only to detect HIV-1, it will not actually detect HIV-2 (Pebody, 2021).

It has also been observed that people infected with HIV-2 tend to have a lower viral load in their blood than people infected with HIV-1. If left untreated, HIV-1 and HIV-2 weaken a person's immune system, leaving them more vulnerable to other infections and diseases. However, HIV-2 tends to evolve more slowly than HIV-1 (Burgess, 2018).

AIDS (acquired immunodeficiency syndrome) is the English abbreviation that defines a complex of different diseases that specifically affect people infected with HIV who due to immunodeficiency develop a series of opportunistic infections. AIDS therefore means the stage in which HIV infection leads to the collapse of the immune system manifested by treatment-resistant infections. Most germs become highly pathogenic when the CD4 level of the HIV-infected person falls below 200 cells per cubic cm of blood (Ignat, 2006: 8-9).

From a medical point of view, AIDS is a sum of symptoms and clinical signs. It is known that B and T lymphocytes protect the human body against viruses, parasites, fungi, etc. The term AIDS was first introduced in 1982. In Russian-speaking countries the term SPID is used, while in China they call it "AI ZI", meaning disease transmitted through love. (Buzducea, 1997: 19).

According to experts from the World Health Organization, most people do not feel HIV-specific symptoms in the first months after infection and may not be aware they are infected. Others may experience flu-like symptoms, including fever, headache, rash, and sore throat. However, the virus is the most infectious when it come to the potential to be passed on (World Health Organization, 2021).

In the opinion of Dr. Ioan Nedelcu, there is an average period of 12 weeks, during which the actual seroconversion takes place, which coincides with the appearance of the first specific antibodies, with specific HIV anti-structures. Deterioration of the functional and structural state of the immune system progressively increases the risk of developing opportunistic infections or cancerous tumors. Viewed from this angle, all these clinical manifestations are present in the final evolutionary stage of AIDS (Nedelcu, 1991: 26-33).

## **1.2 Brief history**

HIV was first confirmed in a man in the Leopoldville region of the Belgian Congo (now Kinshasa, Democratic Republic of the Congo). The sample collected containing positive plasma was called L70, and was obtained in early 1959 and frozen in a specific bank. Thus, the first recognized case of human HIV infection was recorded following tests performed on frozen blood. (Zhu, Korber, Nahmias,*et al.*, 1998).

Another reported case is that of a Norwegian family in the 1960s and is an important episode in the history of the HIV infection, which is reported by researchers at the National Hospital and the National Institutes of Health in Oslo. The case was presented in the British medical journal *Lancet* and is considered to be the first European AIDS case to be documented.

In the Norwegian case, the father, a sailor born in 1946, was first seen by Froland in 1966 and suffered from a number of respiratory illnesses while the sailor's wife, born in 1943, began to have persistent fever, respiratory infections and a few

other symptoms in 1967. A daughter born to the couple in 1967 developed normally for two years, but then suffered a series of bacterial and viral infections. All three died in 1976. (Frøland, Jenum, Lindboe, Wefring, Linnestad, and Böhmer, 1988). Luc Montagnier, a French researcher at the Pasteur Institute in Paris, discovered the human immunodeficiency virus in 1983. Montagnier and his team looked for the pathogen in the inflamed lymph nodes and isolated it from a lymph node biopsy from a patient who was thought to have a pre-AIDS immunodeficiency syndrome. It is called Lymphadenopathy Associated Virus (LAV). Thus, the causal relationship between HIV and AIDS was accepted by the scientific and medical community in 1984 and was further verified by the subsequent isolation of type 2 HIV (Gallo and Montagnier, 2003). Between 1981 and 1984, the evolution of this "phenomenon" was quite rapid. If some of the situations from 1981 have been described above, a series of events are noteworthy for 1982: the Center for Disease Prevention and Control (CDC) publishes in the "Morbidity and Mortality Weekly Report" a brief information on the diagnosis of a new disease for 34 of people from Haiti, very similar to pneumonia, but with unclear etiology. Reports of opportunistic infections and Kaposi's sarcoma have been received at the CDC among Haitians living in the United States. The in vitro immunological findings and the high mortality rate (almost 50%) for these patients are similar to the model recently described in homosexual men and intravenous drug users (Centers for Disease Control and Prevention, 1982).

In May 1985, the US Food and Drug Administration (FDA) approved the ELISA technique as a method of testing for HIV. A large-scale ELISA test system was used for scientific purposes in May 1985 to detect antibodies to human T-cell lymphotropic retrovirus, human T-type III lymphotropic virus – HTLV-III which underwent acquired immunodeficiency syndrome (AIDS) (Johnson, 1987).

Also in October 1985, actor Rock Hudson lost his life to AIDS after publicly declaring that he was infected with HIV. His death drew attention to an epidemic that killed millions of people around the world (History, 1985).

In 1986, after having had several names, the virus that causes AIDS was definitively called the human immunodeficiency virus HIV (Case, 1986).

It is known that until November 1989, only 13 cases of AIDS had been reported in Romania, but at the beginning of 1990 a number of 1,168 cases were reported to the Ministry of Health, out of which 1,094 in children. Thus, in several reporting weeks our country reached this situation recorded in the history of medicine when it comes to HIV / AIDS infection: over half of the cases of pediatric AIDS on the European level came from Romania.

The year 1990 is marked in Romania by the epidemiological explosion of in-hospital HIV infection, which will bring to light new cases of HIV infection and pediatric AIDS in the coming years. On September 25<sup>th</sup> 1991 Romania ratified the WHO Convention on Children's Rights of 1989 and introduces mandatory testing of blood donors in Romania (Popovici, 1991).

### **1.3 Social implications of HIV-AIDS in Romania**

Characteristic of HIV infection is the strong impact of discrimination and stigmatization manifested by society towards those infected with HIV (Sicrea and Andriani, 2021). At the same time, the likelihood of HIV transmission is an element of stress. Along with social rejection, the loss of friends, the multiple crises caused by the

first hospitalization, the start of treatment, the reactions to treatment, the appearance of other diseases, etc. enhance the reluctance to accept the diagnosis (Andrioni, 2019). Stigma and social exclusion have manifested themselves since the beginning of the HIV-AIDS epidemic. The fact that AIDS was first discovered in gay people and then in injecting drug users further intensified the reaction of repulsion and humiliation from the community. In addition, there are many situations where disguised discrimination is difficult to demonstrate and difficult to recognize. The situations in which discrimination against people living with HIV can be encountered are very varied, from the refusal of invasive surgical treatment, education, employment, access to social services, migration, marriage, to the renting of a dwelling or obtaining bank loans (Association Romanian Anti-AIDS, 2007).

It is very difficult for people living with HIV / AIDS or their families to fight not only against the disease, but especially with society. The fight against the disease is sometimes seen as an acceptance of the situation but also a permanent confrontation at the psychosocial level (Andrioni and Petrică, 2019).

The attitude of health educators is essential for good information so that prejudices towards infected people are reshaped to appropriate behavioral patterns. Thus, the concept of normalization of HIV-positive young people is reached through non-discriminatory participation in social life (Dan and Chirilă 2006: 23-24).

Not infrequently, young people living with HIV / AIDS end up in special classes that do not correspond to their cognitive-educational needs. There is no differentiated teaching in these classes. Approximately 20% of HIV-positive children who attend compulsory education courses are integrated in special schools precisely because of the diagnosis and not because of the cognitive-behavioural abilities (Child Hub, 2006: 17-20).

Among the many sociological theories that provide an appropriate approach to the study of HIV transmission prevention, we mention three relevant theories: the theory of symbolic interactionism, ethnomethodology and phenomenological sociology.

The perspective of symbolic interactionism is especially useful in the study of behavior, because it gives a primary role to the concept of interaction that occurs between members of a social group. Moreover, human beings interpret or define the actions of others, without limiting themselves to simply reacting to them. Their response is not developed directly as a consequence of the actions of others but is based on the significance they give to those actions.

This theory is useful for studying the stigma that exists among people living with HIV. Phenomenological sociology reveals how meanings are created in the consciousness of the individual. In other words, how life experiences influence and are part of the relationships established between two or more actors in everyday life and how these meanings can be revealed to an observer. In the field of HIV research, this theory can be applied to study the social aspects of the virus. For example, the study of the social representations of HIV infection in order to understand the perceptions and meanings of the disease by the general population.

Ethnomethodology can be useful in analyzing the actions and interactions of the individual in everyday life. In relation to HIV, it is very useful to understand the perceptions and meanings related to HIV among the general population.

The HIV infection must be seen as a complex and dynamic social phenomenon that acquires different meanings depending on the social and cultural context of each society. These meanings, representations, perceptions, beliefs, values and life experiences will make sense and guide people's behaviour and actions in relation to HIV-AIDS. Moreover, these different values and meanings influence the preventive practices that people adopt against HIV. It is for these reasons that most of the interventions conducted in this field must take into account the social dimension of HIV (Reinado and Hernández, 2015).

People infected with HIV or AIDS are largely protected by common legislation in society. No one has the right to restrict the freedoms and rights of individuals based on their health condition. In order to benefit from the legal provisions and normative acts that regulate the protection of persons with disabilities, persons infected with HIV must be officially registered after diagnosis by laboratory confirmation (ELISA test) of HIV infection.

According to Order no. 725 of 01.10.2002 regarding the criteria on the basis of which the degree of disability is established, published in the Romania's Official Gazette no. 781 of 28.10.2002, HIV-positive children and adults may be ranked into a degree of disability depending on the clinical-immunological stage. The Romanian medical system before 1990 provided that any treatment or medical intervention should be performed when the person was hospitalized for a period of at least 2 days.

For an HIV-positive person, this "minimum" interval could mean hospitalization for life. People with HIV / AIDS need, in addition to medical and psychological treatment, education and social care.

The day outpatient wards were created out of the desire to respond to the multiple needs of these people. They are based on the concept of day hospitalization, which allows the provision of medical services in a non-residential way, allowing the person affected by HIV-AIDS to spend as much time as possible with the family. The Romanian Angel Appeal Foundation introduced this model of day outpatient wards in 1991 integrating medical, counselling, educational and social services within a single ward, namely the day outpatient wards. The existence of a multidisciplinary team makes the social interventions to be performed by the social worker who provides information and support in communicating the diagnosis to both the direct beneficiary and his family. Provides informational and procedural support in preparing the necessary documentation in order to obtain benefits under social protection laws (e.g. preparation of the file for obtaining a monthly food allowance), disability or retirement depending on the case (Romanian Angel Appeal, 2016).

The Ministry of Labour, Social Solidarity and Family, through the Labour Inspectorate, monitors the observance of the right to work of people infected with HIV or AIDS, while the County Employment Agencies provide free services to people infected with HIV or AIDS, namely information and professional counselling, including job search by disease status (UNOPA, 2020: 8).

In the absence of other alternatives, more and more HIV-positive people choose to turn to social protection by applying for retirement with an pension based on the degree of disability. The right to retirement of persons infected with HIV / AIDS is provided by Law 263/2010 with subsequent amendments by Law 197 of July 16, 2021. Thus in the absence of active social protection measures in the case of persons affected by HIV-AIDS social benefits: indemnities, allowances and disability pensions remain

the only form of support. In the absence of active social inclusion measures, dependence on the social protection system is increasing, taking into account that in Romania on December 31<sup>st</sup>2020 a number of 16,848 people living with HIV / AIDS were included in the statistics of the "Matei Balș" National Institute of Infectious Diseases. Thus, Romania still has a large number of long-term survivors, in the age group of 30 - 34 years, who come from the cohort of 1987-1990 (> 5500) ("Matei Balș" National Institute of Infectious Diseases, 2020).

**2. Research methodology. Data analysis and interpretation**

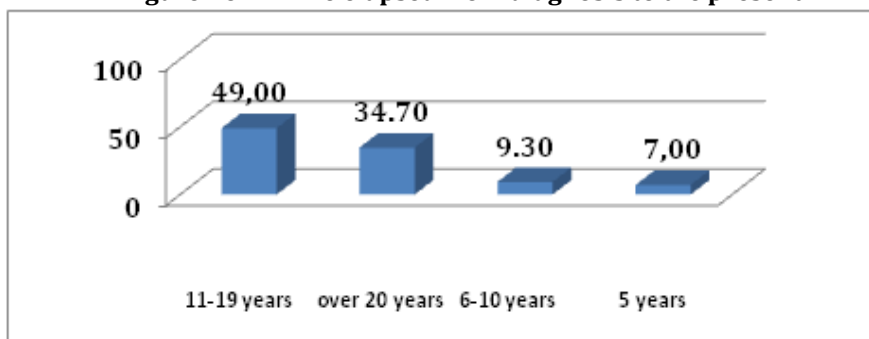
The aim of the research is to identify how social protection measures in Romania promote social inclusion and combat discrimination against people affected by HIV-AIDS in the micro-region of Jiu Valley, Hunedoara County. The research hypothesis was the following: "Revealing a positive HIV diagnosis socially generates discrimination and stigma in the absence of legislative measures to promote social inclusion". The data collection method was the questionnaire-based sociological survey. The studied group consisted of 43 subjects identified through informal therapy and support groups through the "snowball" technique.

**Table no.1 Distribution of subjects by gender**

Subjects Gender	Male	Female	Total
	39.53	60.47	43=100

Over 60% of the subjects participating in the study are female and under 40% are male respondents. During the study, females were much more open.

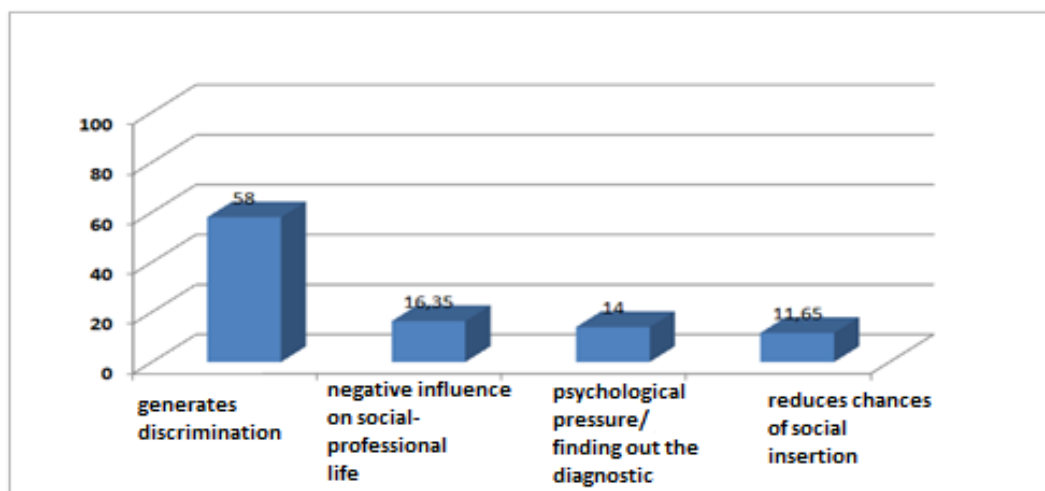
**Figure no.1: Time elapsed from diagnosis to the present**



Most respondents stated that they have been infected for a longer period of time, the first diagnosis of HIV infection being detected more than 15 years ago for 49% of subjects at the opposite pole with only 7% being relatively recently diagnosed in the last 5 years. The time elapsed from diagnosis to the present helps us to better outline the main feature of the study group, namely the existence of long-term HIV diagnosis, which shows that most of the subjects participating in the study come from the so-called "generation 89" when they chain infections were produced in several hospitals in Romania. Thus, most respondents went through all the stages of transition in

relation to HIV infection and the development of all programs for the health and social inclusion of HIV-positive people in our country.

**Figure no. 2. Effects of breach of confidentiality**



Following the responses obtained, 58% of the subjects believe that breach of confidentiality continues to be the main cause of discrimination. They believe that once confidentiality is violated, the immediate consequence is discrimination on several levels: at school, in the health system, in civil society, etc.

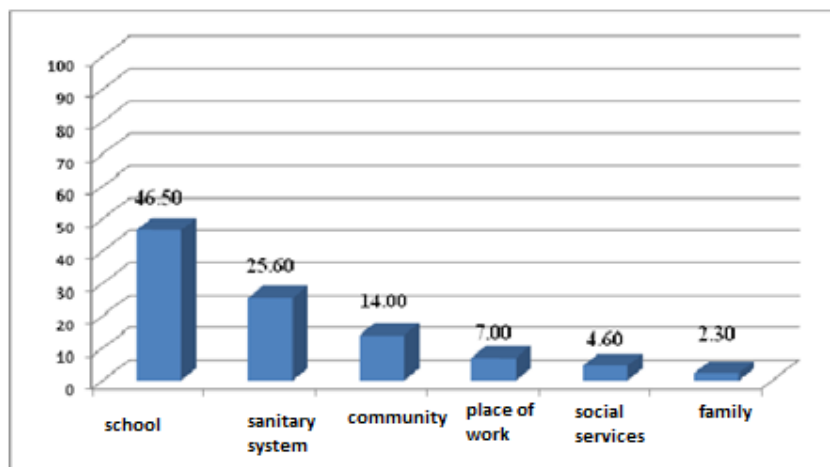
Over 16% of the surveyed individuals believe that once the diagnosis is found by violating confidentiality, the chances of social integration decrease significantly, the society not being ready to accept them. Respondents believe that disclosure of the diagnosis creates a barrier, builds a wall that prevents them from having a normal social life. They say that society is not yet ready to accept HIV-positive people in the true sense of the word.

About 14% say they fear that with the breach of confidentiality the diagnosis may be found, and this creates psychological pressure. The fear of diagnosis leakage on a social level continues to be one of the problems present in people affected by HIV or AIDS. They are often faced with denial of their serological status precisely in order to prevent situations of discrimination. Disclosure of the diagnosis, therefore, continues to be the main fear of people living with HIV / AIDS.

For fear of being exposed, they often send their relatives or next of kins to take their antiretroviral therapy precisely in order to avoid being seen in the HIV-AIDS ward. Most of the time, parents, grandparents or siblings show up to take their antiretroviral medication specific to HIV infection.

Over 11% believe that once privacy is violated, the chances of social integration decrease significantly. The statement of the subjects is that „*people are not ready to accept us as we are, they are still afraid of us*”. Among the respondents , 11% were people who stated that once their diagnosis was exposed, they also encountered problems in the neighbourhood where they live, with people shouting “AIDS people, biological bombs” at them.

**Figure no. 3. Situations encountered in relation to the HIV-AIDS discrimination**



The school continues to be the place where discrimination in relation to HIV infection has manifested itself most severely. Over 46% of the subjects state that the most traumatic events related to discrimination were experienced in school, especially during the first education stage (elementary and middle school) as in the schools of the Jiu Valley there was a real "HIV hysteria" due to the first cases of HIV infection in children officially reported.

For 25% of the subjects the health system is the place where they, as HIV-infected patients, have suffered discriminatory episodes. They stated that several times they were exposed to doctors' refusal to treat them when they found out the diagnosis.

HIV-positive patients believe that the health system is not yet ready to take the blame for the 1985-1992 epidemiological accident.

Although in a smaller percentage, of 14%, the community continues today to be related to HIV discrimination. Respondents say that in 2018, people are not fully able to accept the social reality of HIV infection.

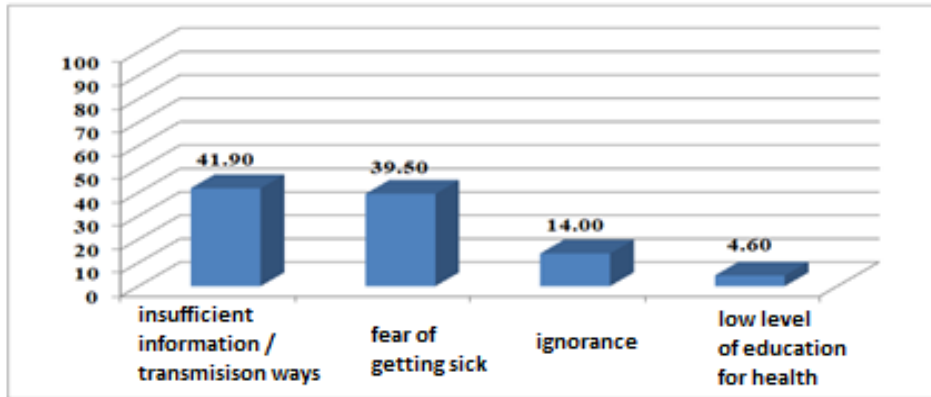
The workplace is also mentioned by 7% of the subjects when it comes to the issue of discrimination against HIV-infected patients. They said they were rejected at various jobs when their serological status was found out.

More than 4% of respondents say they have encountered problems with discrimination and breaches of confidentiality when using social services.

They claimed that instead of being guided and respected for their rights under the law, civil servants in social work services tried to limit them in obtaining social benefits or money benefits, making the procedure for obtaining these rights more difficult. In our country, although HIV infection is classified as eligible for the degree of disability "severe with a companion / personal assistant", some HIV-positive patients do not benefit from these rights being classified in underestimated degrees of handicap, "accented or moderate". This leads to a significant decrease in cash benefits by about 80%.

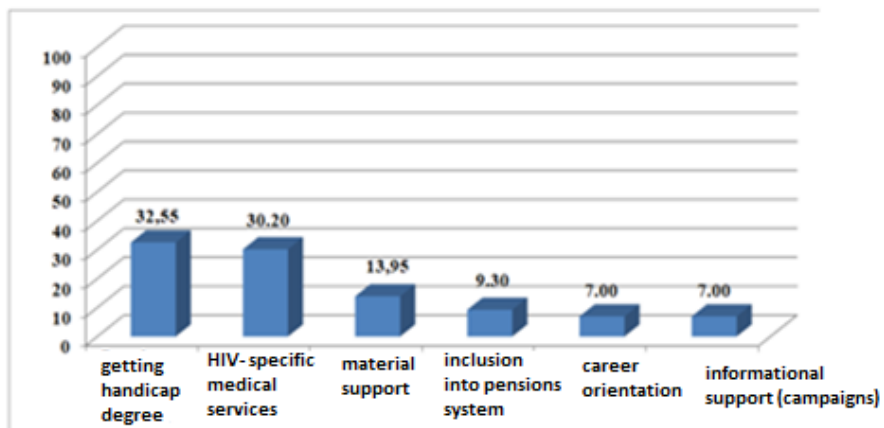


**Figure no. 4. Causes of discrimination in relation to HIV infection**



Regarding the causes that lead to discrimination in the first position, reported by almost 42% of the respondents, ranked the insufficient information on the routes of transmission of HIV infection. Despite numerous information campaigns on the channels of transmission and risk behaviours associated with HIV / AIDS, the main cause of discrimination is the lack of these basic notions in society. Thus, approximately 42% of the subjects believe that better documentation of the mechanisms of infection of the disease, routes of transmission and behaviours at elevated risk of disease could contribute to changing the perception among the general population, without it have a behaviour manifested by repulsion and discrimination in relation to HIV-positive people in Romania. The next position in the opinion of the respondents with over 39% of the answers is the fear of illness. The fear of illness in the opinion of the subjects is given by the lack of information or by the promotion of incorrect and incomplete information by adopting myths about the transmission routes. Ignorance is one of the reasons mentioned by 14% of respondents, who believe that society has become ignorant, do not want to be informed but also to accept HIV-positive people. The low level of health education and the lack of concern of the state in this regard since schooling can be a cause of discrimination in the case of HIV / AIDS, over 4% of patients surveyed declaring it. The respondents believe that the low level of health education is reflected at the collective level through offensive behaviour towards people affected by this disease.

**Figure no. 5. Medical and social protection measures known to the beneficiaries**



The establishment of the disability degree according to law 448/2006, with a percentage of over 32%, is one of the most well-known social protection measures by the HIV-positive people surveyed. In their opinion, their classification in a degree of disability represents both social and material support by offering cash benefits.

HIV-specific medical services in day care (free therapy, periodic biological and immunological evaluation) represent the answer provided by over 30% of subjects.

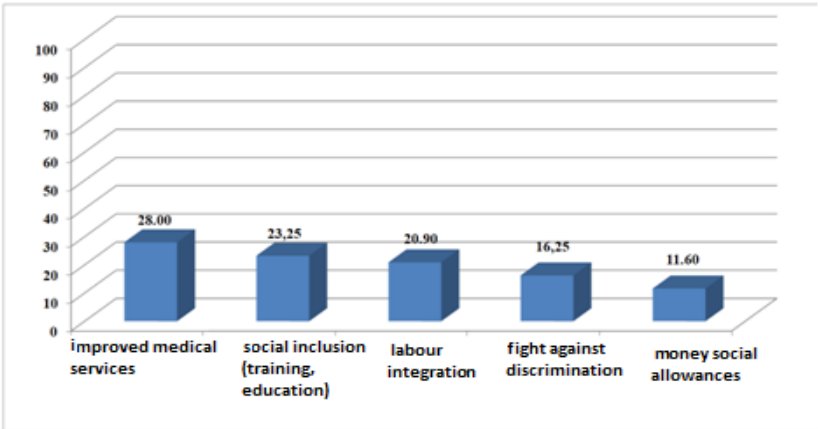
The material support offered by the Romanian state is one of the protection measures that was highlighted by almost 14% of the subjects. The latter argue that this financial aid is the safety net for surviving as and if they cannot get a job. Cash benefits are often the only source of income for an HIV-positive person.

Inclusion in the pension system, namely classification in the degree of disability is for 9% of respondents one of the most important social protection measures. This shows that inclusion in the pension system is a possible solution to obtaining additional income to ensure daily living.

It should be mentioned that along with schizophrenia, epilepsy, neoplasms, HIV is one of the categories in which retirement in the degree of disability can be achieved without a contribution period in the public pension system. Thus, more and more HIV-positive patients, due to the impossibility to find employment, choose retirement. Precisely for these reasons, for only 7% of the subjects, career guidance is a welcome measure of inclusion. From the education point of view, the information support generated by campaigns, seminars, thematic trainings for HIV-positive people is an area of interest for approximately 7% of respondents. They consider such activities to be beneficial for personal development.

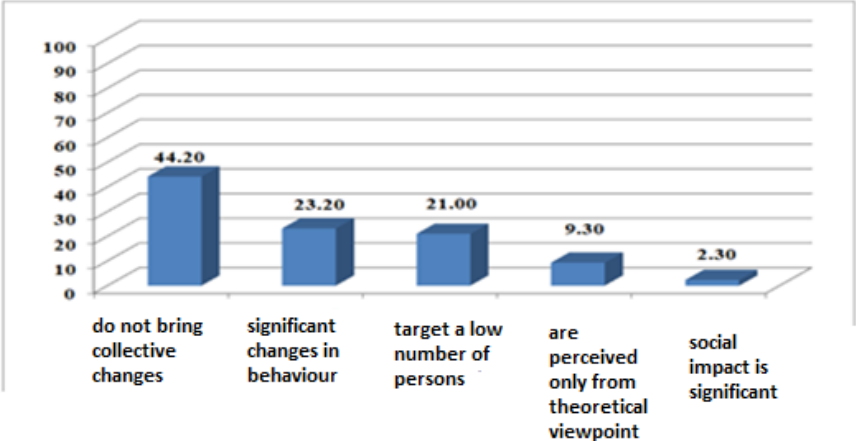
The access to ARV therapy and the classification in a degree of disability according to Law 448/2006 continue to be by far most HIV patients “well-regarded” protection measures offered by the Romanian state. Following these responses, the subjects were asked to imagine that they are decision-makers in the Romanian parliament and have the power to implement social protection measures for HIV-positive people.

**Figure no. 6 Medical and social protection measures proposed by the beneficiaries**



Improving medical services continues to be a priority for HIV-positive patients, with 28% drawing attention upon this issue. Under the generic name of medical services, the respondents motivated their response by the need to ensure uninterrupted treatment with antiretrovirals and to facilitate non-discriminatory access to any branch of medicine. They believe that improving medical services is the first step in leading a life as close to normal as possible. As it is known, the problem of social inclusion is quite common among people affected by this disease. Respondents strongly state the need for changes at the practical level in terms of education, access to differentiated training according to the stage of the disease, access to training and personal development for 23% of respondents. For about 21% of people participating in the study, real labour integration at a practical level continues to be a priority. They consider that facilitating the labour market is the first step towards normality, acceptance and integration. Combating discrimination is the answer given by over 16% of the study's subjects, who believe that even today discrimination continues to be a pressing issue for HIV-positive people. Discrimination in their opinion raises most of the walls, whether we are talking about the workplace, the community, or medical services. Cash benefits in the form of allowances and allowances are the only form of aid applicable to HIV-positive people in the opinion of over 11% of subjects.

**Figure no. 7. The social impact of HIV-AIDS information campaigns**



Information and awareness campaigns on HIV/AIDS do not produce significant changes in the collective mentality. For more than 44% of respondents, they are taken seriously only by a limited number of individuals interested in the subject. In the opinion of the respondents, the campaigns are good, but they do not reach a large segment of the population. One of the possible causes may be the lack of health education programs carried out in stages by age segments since primary school. Just over 23% of young people surveyed believe that once implemented, campaigns produce significant changes in collective behaviour. By informing people, they more easily accept HIV-positive people from a social point of view. The latter say that educating the population about the ways of HIV transmission and at the same time dispelling the myths related to this condition are the first steps towards normalization and acceptance. Over 9% of young HIV-positive respondents say that information

sessions are perceived only theoretically by the uninfected population, the latter not applying into practice what they were taught, namely avoiding risky behaviours and accepting HIV-positive individuals as "socially normal".

Only 2% strongly state that NGO efforts to educate the population about HIV infection have a significant social impact leading to acceptance and non-discrimination of HIV-positive people.

### 3. Conclusions

HIV infection can be successfully managed only when we involve specialists in fields related to medicine (legal, social work, sociology, pedagogy, psychology), because it requires a multidisciplinary approach far beyond medical boundaries. The stigma of the HIV-positive person remains an unresolved issue, discrimination being present both socially and in relation to medical services. One step towards normality is that of health education among the seronegative population to know how to manage relationships with a person affected by HIV-AIDS. Although information campaigns do not produce significant changes among the population at present, they can be used as a tool to educate them in the medium and long run.

Medium- and long-term effective management of HIV infection can be achieved only through measures of socio-medical inclusion of the people affected by this disease by facilitating their access to specific treatment, counselling and guidance, and by promoting social inclusion beyond the cash benefits or disability degree classification.

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