

Accessibility and Effectiveness of Social Security Granted to People Living with HIV and Members of Their Households

Abstract

The paper presents some results of the research concerning the availability and effectiveness of social protection in Ukraine for working-age people living with HIV (PLHIV) and members of their families. The research in Ukraine was carried out by the Social Expertise Centre at the Institute of Sociology of the National Academy of Sciences (NAS) of Ukraine with the financial and technical support of the International Labour Organisation (ILO). This research was a part of the global research conducted in 2012–2013 according to the ILO Programme on HIV/AIDS and the World of Work (ILO/AIDS) to gain the information about the life situation of working-age people living with HIV and their families, as well as about the current state of social security for these persons. Ukraine was one of the four countries participating in this global research, together with Guatemala, Indonesia and Rwanda.

Totally, 800 PLHIV (including 349 persons working in the formal economy, the same number of those who were working in the informal economy and 102 unemployed from five administrative-territorial units of Ukraine such as Donetsk, L'viv, Odesa, Kyiv regions, the Autonomous Republic of Crimea and the city of Kyiv) took part in the research. It was conducted from August to October 2013 in compliance with the research ethics. In particular, respondents (people living with HIV) were interviewed only with their consent; confidentiality of their answers was scrupulously preserved.

The author concentrates her attention on the following aspects: what types of insurance benefits/assistance, state social assistance and social services are provided to the people living with HIV, depending on whether they are employed or not; where do the respondents spend the received insurance benefits/assistance or state social assistance and how do they use social services; what kinds of obstacles deprive people living with HIV of social security.

Keywords: *social security, insurance benefits/assistance, state social assistance, social services, people living with HIV, Human Immunodeficiency Virus.*

Ukraine is one of the countries in Europe and in the Commonwealth of Independent States (CIS) mostly affected by the HIV epidemic. During 1987–2013, 234,257 persons living with HIV (PLHIV) were registered in Ukraine, while 62,288 were reported as AIDS patients. The number of PLHIV under medical supervision at the health care institutions is growing every year. As of July 1st 2013, there were registered 134,302 PLHIV (or 2948 persons per 1,000,000 of population) including 27,181 AIDS patients (597 persons per 1,000,000 of population)¹.

The prevalence rate of HIV is varying from region to region; the highest rate is registered in the southern and eastern parts of the Ukraine (covering Dnipropetrovs'k, Donetsk, Odesa, and Mykolaiv regions, as well as the city of Sevastopol' and the Autonomous Republic of Crimea). However, some regions with limited access to HIV testing may in fact have higher number of new HIV infections than presented in official statistics².

The HIV epidemic continues to be concentrated in the three key groups: injecting drug users (IDU), commercial sex workers (CSW) and men who have sex with men (MSM). The prevalence rate is also high among prison inmates. Recent reports indicate a growing number of the PLHIV infected through sexual contacts, which provokes serious concern because the epidemic is becoming generalised. As of December 2012, 51.1% HIV carriers became infected from unprotected sexual contacts and 28.6% – from injecting drugs. Sexual transmission is mostly connected with harmful sexual behaviour of IDU and their sexual partners, especially women being infected through unprotected sex with HIV-positive male drug users³.

The HIV and AIDS Recommendation, 2010 (№ 200) urges ILO Member States to develop, adopt and effectively implement national policies/programmes for PLHIV and AIDS patients in the business world, covering all persons working in both formal and informal sectors of economy and their families.

In 2011 the tripartite partners in Ukraine – government agencies, employers' associations and trade unions – adopted the National Tripartite Cooperation Strategy on HIV and AIDS in the World of Work. This strategy provides the basis for a coordinated response in main areas of employment. They also adopted the National Strategy for Controlling the Spread of HIV/AIDS including the HIV Prevention Programme, treatment, care and support of HIV-infected people and AIDS patients for the period of 2009–2013. At first, the fight against the HIV/AIDS epidemic was accepted by law. This fact confirms priority of the state in the area of health protection and social development.

¹ HIV-Infection in Ukraine. Newsletter № 40, 2013 // [Electronic resource]. – Access mode: <http://ucdc.gov.ua/attachments/article/86%29.pdf>.

² The Ministry of Health of Ukraine. Harmonised National Report on Progress in the Implementation of Measures in Response to AIDS. Reporting period: January 2010 – December 2011–2012.

³ Analysis of Spreading HIV in Ukraine // [Electronic resource]. – Access mode: <http://infolight.org.ua/content/analiz-poshirennya-vil-infekciyi-v-ukrayini>.

In addition, the Cabinet of Ministers of Ukraine adopted the Decision of July 11, 2007 establishing the National HIV/AIDS/STI/TB¹ Council, a consultative and advisory body under the Cabinet of Ministers.

The system of social security in Ukraine is very comprehensive. Different privileges, social benefits and social services are available, regulated by 58 laws and more than 120 by-laws. Universal health care is provided to all Ukrainians under the Act 280 I-XII (1992).

Social security equally covers all citizens in Ukraine, including men and women living with HIV.

The Act of 1991 (amended in 2010) provides for prevention, treatment, care and support for HIV-related illnesses, as well as ensures legal protection and social security for PLHIV. The Act guarantees the rights to information, work and free antiretroviral therapy (ART) for PLHIV.

Medical assistance seems to be the most important aspect of social security since it plays an important role in HIV prevention and reduces the vulnerability of target group. Medical assistance is provided by health care institutions of the Ministry of Health of Ukraine, AIDS centres, and by HIV/AIDS non-governmental organisations (NGOs). The vast majority (95%) of respondents, irrespective of their employment status, were reported to have access to ART (97% of men and 93% of women), even though they might not currently use it.

The above research also revealed that 82% of PLHIV received assistance from the national public health organisations, 26% from Ukrainian NGOs, 24% from the social security institutions, 15.5% from international organisations, 4% from municipal utilities, 2% from employers, and 0.6% from trade unions.

The proportion of PLHIV who received social insurance benefits/assistance is significantly greater (31%) compared with 8.5% who received state social assistance. State social assistance received by PLHIV is mainly spent on food, daily needs, utility services, transportation and payments for doctor consultation and medication.

The Ukrainian legislation also provides for wide use of substitution therapy (ST) for injected drug users to reduce the risk of HIV-infection and improve attitude towards ST among population.

One of the goals of our research was to find out what types of insurance benefits/assistance, state social assistance or social services are received by PLHIV depending on whether they are employed or unemployed.

A special role in the system of social security belongs to social security measures, which in their turn consist of insurance benefits/assistance and state social assistance.

The social security measures are classified according to the types of social risk: disease, pregnancy and childbirth, care and upbringing of children, job loss and unemployment, workplace injury, disability, death of a breadwinner, and an old age.

The types of insurance benefits/assistance included into the questionnaire are as follows:

- unemployment benefits;

¹ Acquired Immunodeficiency Syndrome/Sexually Transmitted Infections/Tuberculosis.

- social pensions;
- disability pensions;
- pensions paid in the case of a breadwinner's loss;
- funeral costs;
- temporary disability benefits;
- total and permanent disability benefits;
- maternity benefits (in the case of pregnancy and childbirth);
- paid sick leave in the case of falling ill;
- benefits for industrial injuries and occupational diseases.
- State social assistance includes the following subsidies:
- state assistance to parents with dependents;
- low-income family supplement;
- financial aid for invalids since the childhood and for children with disabilities;
- monthly allowances for HIV-infected children and children with HIV-related diseases;
- social assistance to the disabled and persons who are not eligible for a pension.

Table 1

Social insurance benefits/assistance and state social assistance received by respondents in the last 12 months, according to the employment type and gender, %

Variants of social benefits/assistance and social assistance	Employed in the formal sector	Employed in the informal sector	Unemployed	Total		By gender	
				N	%	Men	Women
1	2	3	4	5	6	7	8
Social insurance benefits/assistance							
Unemployment benefits	2	3	2	22	3	3	3
Social pensions	0	0	1	1	0.1	0.2	0
Disability pensions	15	18	25.5	142	18	18	17.5
Pensions paid in the case of a breadwinner's loss	1	0.3	0	4	0.5	0	1
Funeral costs	0	0.3	1	2	0.3	0	0.5
Temporary disability benefits	0.6	0.3	1	4	0.5	0.7	0.3
Total and permanent disability benefits	-	-	-	1	0.1	0	0.3
Maternity benefits	1.4	2	8	20	2.5	0	5.2
Paid sick leave	13	1	2	50	6	6	7
Benefits for industrial injuries and occupational diseases	1	0	0	4	0.5	0.5	0.5

End of table 1

1	2	3	4	5	6	7	8
State social assistance							
Low-income family supplement	0.6	2.3	1	11	1.4	1	2
State assistance to parents with dependents	2	1.4	0	11	1.4	0.2	2.6
Financial aid for invalids since the childhood and for children with disabilities	0.3	0.3	0	2	0.3	0.2	0.3
Monthly allowances for HIV-infected children and children with HIV-related diseases	0.6	0.6	1.0	5	0.6	0	1.3
Social assistance to the disabled and to the persons who are not eligible for a pension	2	5	6	30	4	4.1	3.4
The assistance is not received although the respondent is eligible	44	38	48	334	42	44	40
The assistance is not received because the respondent is not eligible for it	9.5	10	0	68	8.5	8.6	8.4
The assistance is not received and there is no idea whether the respondent is eligible or not for it	17	21.5	9	144	18	18	18

N (total number of respondents) = 800.

So, what social insurance benefits/assistance or types of state social assistance are received by people living with HIV?

Experience of Receiving Social Insurance Benefits/Assistance

According to the research, 31% of respondents received social insurance benefits/assistance in their own name, 8% of respondents – in the name of their spouses, 3.5% – in the name of the respondent's children and 17% respondents – in the name of other members of the respondent's family.

Among the above-mentioned types of social insurance benefits/assistance the respondents mostly receive disability pension (18%), paid sick leave (6%), unemployment benefits (3%) and maternity benefits (2.5%).

Structure of the respondents' answers to this question does not correlate with gender, with the exception of "state aid to parents with dependents", which is paid to women in most cases (2.6% compared with 0.2% of men). Men's share is

slightly bigger than women's one among those who do not receive benefits/assistance despite being entitled to them.

The structure of the respondents' answers to this question varies slightly depending on the respondents' category (employed in the formal/informal sector or unemployed).

So, disability pension tops the list of social insurance benefits/assistance received by all categories of respondents. Then follows paid sick leave (for respondents employed in the formal sector), unemployment benefits (for those who work in the informal sector), and maternity benefits paid mostly to unemployed young women (43% unemployed women are from 25 to 35 years of age).

Experience of Receiving State Social Assistance

The results of our research show that 8.5% of respondents received state social assistance in their own name, 1% – in the name of their wives/husbands, 7% of respondents – in the name of their children, and 1% of – in the name of other family members.

Among the proposed list of the state social assistance types the respondents mostly receive (in their own name) social assistance to the disabled and to the persons who are not eligible for pension (4%), low-income family supplement (1.4%) and assistance to parents with dependents (1.4%).

There are only 0.6% of respondents, mainly HIV-infected children and children with HIV-related diseases, who receive monthly allowances. Today this assistance does not exceed 170 UAH per month.

The answers given by respondents to the question about receiving state social assistance are mainly the same irrespective of the respondent's category (working in the formal/informal sector, the unemployed).

In accordance with the national legislation, all citizens of Ukraine, irrespective of whether they work in the formal or informal sectors of economy or are unemployed have the right to appeal to the state authorities and request social security benefits or services budgeted for in the national budget or locally (including state assistance to parents with dependents, low income family supplement and assistance for children with disabilities). This assistance also includes provision of employment services, professional training and skills improvement services, as well as subsidies for housing and utility services, etc.

The interviews show that a significant portion (42%) of respondents did not receive any insurance benefits/assistance or state social assistance, although they are eligible for them. All the reasons for which the eligible respondents did not receive insurance benefits/assistance or state social assistance can be divided into three groups: 1) reasons related to poor respondents' awareness of their personal rights; 2) procedural reasons when people have to deal with complicated application procedures and long queues; 3) unwillingness to disclose their HIV status because of fear of being discriminated.

Thus, analysing various kinds of social security, one should pay attention to the fact that the dominant type of social security for PLHIV is insurance benefits/assistance because the share of PLHIV who receive them is significantly greater (31%) in comparison with those who receive state social assistance (8.5%). However, such a situation is common to all forms of social security, where

the dominant role belongs to social benefits and privileges. These types of social security have been common ever since the Soviet times, and they are based mainly on a “formal” approach ignoring real needs of material assistance for socially disadvantaged categories of the population (including PLHIV), as well as the real value of provided benefits and services.

The Respondents' Estimations on the Size of Social Insurance Benefits/Assistance and State Social Assistance

According to the Constitution of Ukraine (Article 46), citizens have the right to social security, which includes the right to receive an assistance in the event of total, partial or temporary disability, loss of a breadwinner, unemployment due to circumstances beyond their control, as well as in case of getting old age and in other cases stipulated by the law. The exercise of this right is guaranteed by general, compulsory state social insurance funded through insurance premiums paid by citizens, enterprises, institutions and organisations, as well as from the national budget and other funding sources for social security system; besides, through establishment of a network of state, municipal and private institutions for the care of incapacitated people. Pensions and other types of social payments and assistance that are the main sources for supporting life of this category must be sufficient to ensure the standard of living not lower than subsistence level established by the law.

Table 2

The respondents' estimations on the monthly size of insurance benefits/assistance and state social assistance (actual and desired), in UAH

Variants	Working in the formal sector		Working in the informal sector		Unemployed		Received			Desired		
	Received	Desired	Received	Desired	Received	Desired	Total	Men	Women	Total	Men	Women
Insurance benefits/assistance	427	2193	399	2071	539	2283	432	419	446	2155	2158	2151
State social assistance	425	2360	439	2195	544	2411	439	389	492	2299	2300	2297

Do social insurance benefits/assistance or state social assistance received by respondents enable to maintain living standards at least at subsistence level established by the law?

According to the interviews with PLHIV respondents (See Table 2), the average size of insurance benefits/assistance received by them amounts to 432 UAH per month.

The largest average size of insurance benefits/assistance is 539 UAH (for the unemployed). Employees in the formal sector receive on average 427 UAH per month, while those who work in the informal sector — only 399 UAH.

Desired size of insurance benefits/assistance, in respondents' opinions, should be almost five times larger — about 2155 UAH per month¹.

According to the respondents' answers, the average size of state assistance is equal to 439 UAH per month, which is almost the same amount as being paid in the form of insurance benefits/assistance. But its desired size should be five times more — 2299 UAH.

The largest average size (544 UAH per month) of state social assistance is provided to the unemployed. The smallest (413 UAH) is paid to those who work in the informal sector of economy. Employees in the formal sector receive on average 425 UAH per month.

It is also necessary to note that average insurance benefits/assistance and state social assistance for women (446 UAH and 492 UAH per month respectively) are a bit higher than those for men (419 UAH and 389 UAH). So, according to the research results, the average size of both insurance benefits/assistance and state social assistance paid to PLHIV is quite low. Depending on the category of respondents, difference in the average monthly size of insurance benefits/assistance and state social assistance may be about 100–150 UAH.

We would like to remind that PLHIV together with their family members receive different kinds of insurance benefits/assistance and state social assistance. Therefore, one would assume that the standard of living of these families is adequate to meet their basic needs (food, clothing, medical care, etc.) and does not fall below the subsistence level.

However, considering the level of aggregate monthly income per household member, we saw that one third (34%) of the respondents received less than 1108 UAH (that is the subsistence level). Income of the other 44% of respondents did not exceed 2000 UAH.

At the same time, there are twice as many unemployed PLHIV (75%) with income below or equal to the subsistence level as those who work in the informal sector of economy (38%) and four times as many as those who work in the formal sector of economy (19%).

What is the major cause of such a situation? According to the results of in-depth interviews with key informants, almost all experts believe that most of the benefits, social and compensatory payments stipulated by the law are not sufficient to mitigate the negative consequences of economic transformation in Ukraine and practically are not able to reduce poverty among this category of population.

“These benefits seem very small, actually miserable. I think they cannot improve living standards and quality of life of these people. Food, medicines, and other things that these patients need are too expensive today, so, it is quite clear that compensations that they receive are insufficient” (state employee, man).

Let us consider where respondents spend the money they received as insurance benefits/assistance and in the form of state social assistance. The respondents' answers were distributed as shown below:

- buying food — 80%;

¹ Minimum wage in Ukraine at the time of interview was 1147 UAH (i. e. 143 USD).

- covering other daily needs – 76%;
- purchasing medicines – 69%;
- utility payments – 61%;
- transportation payments – 54%;
- paying for doctor consultations – 23%.

Table 3

**The answers given by respondents to the question:
“Where do you spend insurance benefits/assistance or state social
assistance that you receive?”, %**

Variants	Working in the formal sector	Working in the informal sector	Unemployed	Total N = 281		By gender:	
				N	%	Men	Women
Buying food	75	82	90	225	80	80	80
Covering daily expenses	71	80	80	213	76	78	73
Purchasing medicines	62	74	75	194	69	70	69
Utility payments	58	59	75	171	61	57	64
Transportation payments	46	61	55	151	54	56	52
Paying for doctor consultations	25	21	25	65	23	17	29

As can be seen in Table 3, the structure of respondents' answers is almost the same irrespective of the category they belong to. Insurance benefits/assistance and state social assistance received by respondents are spent to satisfy their basic needs (food, medicines, etc.) and to cover other daily expenses.

The share of women who spend insurance benefits/assistance and state social assistance on doctor consultations is almost twice as large as those of men (29% and 17% respectively). Besides, 64% of women vs. 57% of men spend their benefits to pay for utilities.

The research results show that insurance benefits/assistance and state social assistance received by respondents do not really contribute to raising living standards of PLHIV and their families. Financial conditions (34%) of these people remain quite poor, especially it concerns families with children under the age of 18 and families with disabled or out-of-work persons. This fact demonstrates that the mechanisms of social support provided by the state are inefficient today. Certain types of social benefits/assistance are granted without due regard to real incomes of citizens (households) who apply for assistance.

Available Types of Social Services

Social services as another component of the general social security system are granted to all citizens of the country who encounter life difficulties and cannot cope with them in order to solve their life problems. The list of these services was

presented in the questionnaire in accordance with the provisions of the Law of Ukraine “On Social Services”¹.

The main forms of social services also include financial aid.

According to the Law of Ukraine “On social services” the following services can be provided:

- social domestic services such as: home delivery of food products and hot meals, hard and soft goods, means of small-scale mechanisation; transportation services, social domestic patronage, facilitation of social and home adaptation, call for a doctor, purchase and delivery of medicines, etc.;
- counselling and psychological services: consultations on mental health problems and advice on improving relations with social environment, using psychodiagnostic methods for studying socio-psychological characteristics of a person with the aim of his/her psychological correction or psychological rehabilitation, methodological support;
- socio-pedagogical services: identifying and promoting further development of diverse interests and needs of persons enduring adverse life circumstances, organisation of individual training, education and correction, arrangement of leisure, sports, recreational, technical and artistic activities, etc., as well as ensuring involvement of these persons into work of various institutions, NGOs and stakeholders;
- socio-medical services: consultations on preventing emergence and development of organic mental disorders among PLHIV, maintaining, supporting and protecting health of these persons, implementation of preventive, therapeutic and health-improvement measures, occupational therapy;
- socio-economic services aimed at satisfaction of material needs of persons enduring adverse life circumstances. These services are provided in the form of financial aid or in-kind support (food, clothing, medicines, furniture, etc.) and as one-time compensatory payments;
- legal services: consulting on current legislation issues, protection of rights and interests of persons who are in difficult life circumstances, facilitation of the state coercion and enforcement of legal liability of those who have resorted to illegal actions in respect of the person with HIV/AIDS (preparation of juridical documents, protection of rights and interests of the person, other types of legal aid, etc.);
- job search services: finding suitable jobs, employment assistance and social support for employed persons;
- information services: providing the information needed to solve difficult life situations (reference services); distribution of educational and cultural knowledge (instructive services); dissemination of the objective information concerning customer properties and types of social services, formation of certain ideas and attitudes of the society towards social problems (advertising and promotion services);
- other social services.

¹ See for details: Proceedings of the Verkhovna Rada (Supreme Council) of Ukraine, 2003, № 45, Art. 358.

The entities providing social services can render them in other forms, not stipulated by this article of the law, but designated by the Cabinet of Ministers of Ukraine as belonging to the list of chargeable social services.

The Law of Ukraine "On Social Services" has created an opportunity to involve some non-governmental organisations and institutions into providing social services. In accordance with Article 12 of the Law of Ukraine "On Social Services", the sphere of social services is based on the use and development of all forms of ownership and consists of public and non-governmental sectors.

Public sector of social services includes state-owned entities managed by central executive bodies.

Communal sector of social services includes municipally owned institutions and establishments subordinated to the local self-government authorities.

Under Article 9 of the Law of Ukraine "On Social Services", in order to get needed social services that are provided by the state and communal entities, a person should apply in writing to the local executive authority or to the local self-government body.

The non-governmental sector includes NGOs, charities, religious organisations and individuals whose activities are related to the provision of social services. Management of this sector is carried out in the manner prescribed by current legislation and relevant statutes.

In order to get social services provided by non-state entities, a person that needs them should address to the relevant entity.

In case a person who needs social services due to his/her age or for health reasons is unable to make a decision whether or not to receive these services, such a decision may be taken by a guardian or trustee as well as by guardianship or tutorship agencies, but in accordance with the provisions of current legislation.

According to the research data, the overwhelming majority (82%) of respondents (655 persons) received social services/assistance from public health organisations. The second place was occupied by non-governmental organisations (26% of respondents applied to them), the third place by social security institutions (24% of respondents addressed to them), the fourth place went to international organisations (15.5% of respondents received social services/financial aid from them) and the fifth place (4% of respondents) – to municipal utilities (housing society management units, transportation facilities, etc.). The share of employers and trade unions among social service providers was insignificant: only 2% and 0.6% of respondents, respectively, applied to them for assistance (See Table 4)¹.

As can be seen in Table 4, socio-medical services (doctor consultations, preventive and therapeutic measures, ART, etc.) provided by national public health organisations took the first place, since 96.5% of respondents have received these services from these institutions in the last 12 months.

Social domestic services (delivery of food products, transportation services, purchase and delivery of medicines, etc.) were provided mainly by international organisations (77% of respondents applied to them), social security institutions

¹ Sum of percentages exceeds 100, because respondents could receive social services/financial aid from several organisations.

(67.5% of respondents addressed to them), Ukrainian NGOs (55% of respondents received services from these organisations) and municipal utilities (49% of respondents applied there).

Table 4

Social services received by respondents or their family members from different organisations in the last 12 months, %

The list of variants	From the employer (at the workplace), N = 17	From the trade union, N = 5	From the social security institution, N = 191	From the municipal utility (housing management, transportation, etc.), N = 35	From the national public health organisation, N = 655	From the Ukrainian NGO, N = 210	From the international organisation, N = 124
Social domestic services	29	60	67.5	49	20	55	77
Psychological services	6	20	38	20	14	45	10.5
Socio-pedagogical services	6	-	15	3	1	4	2
Socio-medical services	35	20	52	31	96.5	51	16
Socio-economic services	18	-	36	3	7	8	2
Legal services	6	-	24	-	3	41	6
Job search services	23.5	-	11.5	-	0.3	4	1
Information services	-	-	18	31	27	54	8

Only 17 persons from the total number of respondents received social services from their employers and 5 persons from trade unions. These are basically social-domestic and socio-medical services.

It should be noted that the respondents' answers concerning social services/assistance were distributed almost in the same way irrespective of the category the respondent belongs to (working in the formal/informal sector or unemployed) and gender.

Thus, according to the research data, now the state-owned sector is the major provider of social services in Ukraine since it covers the needs of the vast majority of respondents (as previously mentioned, 82% of them received social services from the national public health organisations and 24% from the social security institutions). Another distinctive feature of the social services market is a large number of international organisations and NGOs protecting the interests of those who endure adverse life circumstances: 15.5% of respondents received social services from various international organisations and 26% from NGOs. Public sector provides mainly socio-medical services, while social domestic, consult-

ing and legal services belong to the competence of international organisations and NGOs.

The Main Problems on the Path to Receiving Social Services/Assistance

Although the majority of respondents have access to social services, almost 20% (every fifth respondent) noted that these services were inaccessible. As shown in Fig. 1, social services are less accessible to those who work in the formal economy. The unemployed and women compared with men (20% and 17% respectively) have the least access to these services. Such a situation causes serious problems for them.

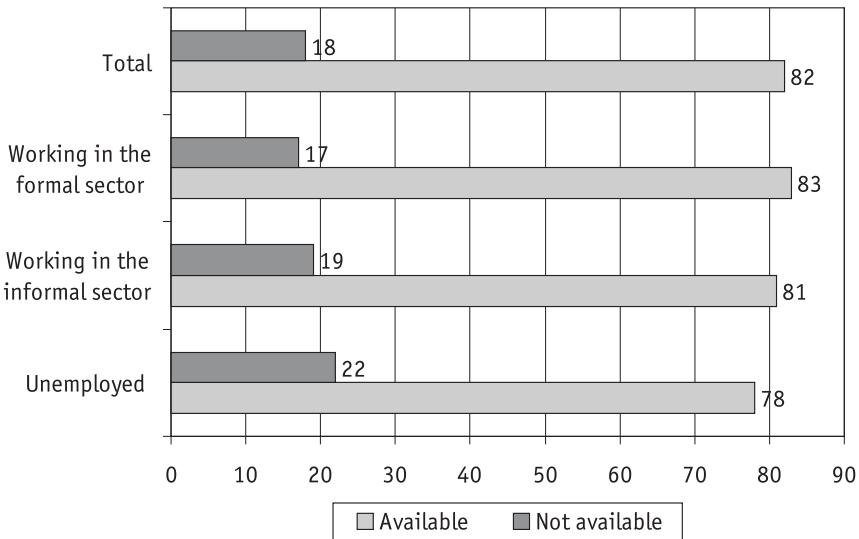


Fig. 1. The respondents' estimations on the accessibility of social services/assistance to them and their family members

The research has revealed a slight difference in ranking principal problems on the path to receiving social services/assistance depending on the organisation type (state-owned institutions or non-governmental organisations; for more details see Table 5). However, the structure of respondents' answers does not differ significantly depending on whether the respondent works (in the formal/informal economy) or is unemployed). Correlation between the principal problems in receiving social services/assistance and the respondent's gender was not significant either. At the same time, lack of certain services concerns more men than women (23% and 14% respectively of those who applied to the state institutions, 15% and 2% of those who addressed to non-governmental organisations). Besides, male respondents are more concerned about the lack of flexible work schedule, which hinders the respondent's opportunities in applying for social assistance (10% of men compared with 5% of women who applied to the state institutions and 13% of men compared with 2% of women who addressed to non-governmental organisations mentioned this problem).

67% of respondents who applied to the state institutions and 51% of those who addressed to non-governmental organisations identified the lack of information about available types of social services/assistance as the main obstacle to receiving assistance.

25% of respondents who officially applied to the state institutions for assistance reported that the application procedure was too complicated for them. It was the second main obstacle to receiving social services/assistance. 18% of respondents noted the absence of necessary services or types of social assistance, and 16% were dissatisfied with quality of services/assistance they received.

15% of respondents who addressed to non-governmental organisations noted that these institutions are located too far from their place of residence. Then followed too complicated application procedure and the absence of necessary services or types of social assistance (11% and 8% respectively were concerned with these problems).

The problem of too remote location of non-governmental organisations providing social services/assistance for PLHIV is rather acute. Most NGOs are based in big cities, therefore those who live in small towns or villages cannot receive the services (or assistance) they need.

Table 5

**The respondents' estimations of basic obstacles
to accessing social services/ assistance from the state institutions
and non-governmental organisations, %**

Basic obstacles	State institutions, N = 147 (18.4%)						HIV/AIDS non-governmental organisations, N = 84 (10.5%)					
	Working in the formal sector	Working in the informal sector	Unemployed	Total	By gender		Working in the formal sector	Working in the informal sector	Unemployed	Total	By gender	
					Men	Women					Men	Women
1	2	3	4	5	6	7	8	9	10	11	12	13
Lack of information about available types of social services/assistance	60	73	68	67	67	68	49	43	79	51	50	52
Too complicated application procedure	17	33	23	25	27	23	9	6	29	11	10	11
Absence of necessary services/types of social assistance	21	15	23	18	23	14	9	6	14	8	15	2
Poor service quality	19	18	5	16	17	16	9	0	7	5	5	5

Continuation of table 5

1	2	3	4	5	6	7	8	9	10	11	12	13
The institution providing social services/assistance is too far from the respondent's place of residence	12	15	5	12	14	10	9	23	14	15,5	18	14
The respondent cannot officially apply for social assistance for the fear of being discriminated in the workplace	12	9	0	9	9	9	9	3	0	5	3	7
Mandatory registration for receiving social services/assistance	9	9	14	9,5	9	10	3	0	7	2	3	2
The respondent has no opportunity to apply for assistance due to the lack of flexible work schedule	9	8	5	7,5	10	5	11	6	0	7	13	2
The respondent has no opportunity to apply for assistance because of inconvenient working hours	9	3	5	5	1	9	0	0	0	0	0	0
Certain services are too expensive for the respondent (or his/her family)	0	6	9	4	4	4	0	3	0	1	3	0
The respondent does not receive any social services/assistance	0	3	0	1	3	0	14	31	0	19	18	21

End of table 5

1	2	3	4	5	6	7	8	9	10	11	12	13
The respondent has not encountered any problems while applying for assistance	2	0	0	0	1	0						

As already mentioned, the major obstacle to receiving social assistance is lack of information about available types of social services/assistance. Therefore, in order to improve the provision of social services/assistance for PLHIV both state-owned institutions and non-governmental organisations should organise various information campaigns among people living with HIV aimed primarily at explaining how to apply for social assistance. These steps would keep PLHIV informed about benefits and services available to them, as well as about registration and application procedures necessary to receive social services/assistance.

According to Ukrainian legislation, social services are provided both free of charge and on a fee-paying basis. The citizens who are not able to take care of themselves due to old age, illness, disability and do not have any working-age relatives who can give them help and support, have the right to free social services.

Social services that are not included into the list of free services stipulated by national standards should be delivered on a fee-paying basis. Social care departments provide necessary services on a fee-paying basis to seniors who have working-age relatives that should care for them.

Table 6

**The answers given by respondents to the question:
“Were social/medical services provided to you free of charge?”, %**

The list of problems (obstacles)	State-owned institutions		N = 778 (97.3%)				HIV/AIDS non-governmental organisations, N = 452 (56.5%)				
	Working in the formal sector	Working in the informal sector	Unemployed	Total		Working in the formal sector	Working in the informal sector	Unemployed	Total		
				N	%				N	%	
Yes, always	74	78	76	594	76	79	84	89	371	82	
Yes, though there were some cases when I had to pay	16	14	21	123	16	3	6,5	9	24	5	
No, I always had to pay for these services	9	8	3	61	8	18	9,5	2	57	13	

Fee-paying social services defined by national standards are provided with the use of differentiated fees. The procedure for provision of social services with

the use of differentiated fee system was approved by the Decree of the Cabinet of Ministers of Ukraine, № 1184 (December 19, 2012). The fees for providing social services to a person who needs them shall be at the rate of 12% of his/her average monthly income for the last 6 months. Differentiated fees are calculated on the basis of tariffs for chargeable social services.

According to the research results, the overwhelming majority of respondents, irrespective of their employment status, always receive social/medical services on a free basis: 76% of respondents from state-owned institutions and 82% from NGOs (See Table 6).

The share of respondents who always had to pay for social or medical services was higher among those who applied to the HIV/AIDS non-governmental organisations (13%) compared with those who addressed to the state institutions (8%).

Conclusions

In general, the research results confirm that people living with HIV face numerous problems in their daily lives. Though benefits and rights for this category of people are guaranteed by Ukrainian legislation, many of them encounter difficulties when trying to receive social services/assistance they need. Some people are not even aware of social assistance, home care services, various benefits and compensatory payments as an important component of the social security system where HIV-infected persons should apply, especially due to change in their employment status.

Lack of information about available types of social services/assistance for PLHIV, complicated application procedures, discrimination and stigma they experience when trying to receive social and health care services, difficulties in access to many kinds of social security benefits, bribery incidences they encounter when applying for social or medical assistance, low benefits and compensatory payments along with other problems existing in the social security system should not remain unsolved since they essentially impair living standards of PLHIV and their families. The research has shown that unsubstantiated and mostly negative ideas of the social security system expressed by respondents do not quite objectively reflect the real situation in this sphere.

According to the research data, the amount of social security benefits (social and health care services, insurance benefits, compensatory payments, etc.) makes a significant portion of the aggregate income of PLHIV, especially among unemployed respondents. So, the share of social security benefits in aggregate household income averaged 16% for the respondents working in the formal economy, 20% for those who work in the informal sector, and 38% for the unemployed.

The money received by respondents as insurance benefits/assistance and in the form of state social assistance is spent mainly for buying food, covering other daily needs, purchasing medicines, paying for doctor consultations, utility payments and transportation payments.

However, neither insurance benefits/assistance nor the state social assistance can improve living standards of PLHIV and their family members. In most cases, they are only able to maintain living standards of this category of population at subsistence level established by the law. Material circumstances of the one

third (34%) of PLHIV families remain quite poor, especially it concerns families with children under the age of 18 and families with disabled or out-of-work persons. This fact demonstrates that mechanisms of social support provided by the state are inefficient today. Besides, certain types of social benefits/assistance or state social assistance are granted without due regard to real incomes of citizens (households) who apply for assistance. This issue requires special consideration in the course of social security reform.

According to the respondents' estimations, socio-medical services (consultations on preventing emergence and development of organic mental disorders among PLHIV, maintaining, supporting and protecting health of these persons, implementation of preventive, therapeutic and health-improvement measures, occupational therapy, etc.) provided by national public health organisations take the first place among all types of social services for PLHIV. Moreover, the great majority of respondents receive these services including antiretroviral therapy free of charge.

However, one cannot avoid mentioning the fact that almost every fifth respondent has no access to certain social/medical services. Most respondents think that the major obstacle to receiving social assistance from relevant institutions is lack of information about available types of social services/financial aid. Hence, in order to improve the provision of social services/financial aid for PLHIV both state-owned institutions and non-governmental organisations should organise information campaigns among population including people living with HIV. These steps would make PLHIV aware of benefits and services available to them, as well as of registration and application procedures necessary to receive social assistance.

Apart from various difficulties in access to certain kinds of the social security benefits or state social assistance, respondents reported experiencing biased attitude and unfriendly treatment towards themselves, bribe payment requests when applying for social or medical assistance. Such a situation indicates the need to carry out instructional and educational activities, first of all for medical staff and social workers in order to foster more tolerant attitudes towards people living with HIV.

Besides, development of HIV/AIDS prevention programmes for Ukrainian enterprises and implementation of the health care reform are also of extreme importance.

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Edited by Olha Maksymenko