



“Alexandru Ioan Cuza” University, Iași
Faculty of Philosophy and Socio-Political Sciences
Doctoral School
SOCIOLOGY Department

**THE RIGHT OF HIV INFECTED CHILDREN AND
YOUNG PEOPLE TO THE HIGHEST ATTAINABLE
STANDARD OF HEALTH IN ROMANIA**



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Iași
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- Dissertation summary –

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TABLE OF CONTENTS

Glossary	5
List of acronyms	7
List of figures and tables.....	8
Abstract.....	9
Introduction.....	14
Chapter I. Sociological perspectives of the HIV infection/AIDS.....	19
1.1. General framework of conceptualization of the HIV infection/AIDS	21
1.2. Brief history of the HIV infection/AIDS	22
1.3. Population group exposed to the HIV infection/AIDS	26
1.4. HIV/SIDA –medical considerations	27
1.4.1. Transmission of the virus.....	28
1.4.2. Symptoms.....	30
1.5. Particular aspects of the HIV infection/AIDS in Romania.....	31
1.5.1. Current national statistics regarding HIV/AIDS	32
1.5.2. Psycho-social implications of the HIV/AIDS in Romania....	35
Conclusions.....	38
Bibliography	39

Chapter II. Socio-legal considerations regarding the right to the best health state possible of children and young people with HIV/AIDS

2.1. Legal framework regarding the protection of children’s rights42

 2.1.1. The origin of the children’s rights42

 2.1.2. Brief history concerning the laws on children’s rights in Romania45

 2.1.3. Children’s rights from the perspective of the new sociology48

2.2. Legal regulations regarding the rights to the best health state possible of children and Young people with HIV/AIDS52

 2.2.1. Conceptual delimitations regarding the right to the health state possible.....53

 2.2.2. The right to the best health state possible of the seropositive children and young people in the international context.....59

 2.2.3. The right to the best health state possible of the seropositive children and young people in the national context63

 2.2.4. Social policies and programmes addressed to the seropositive children and young people in Romania69

Conclusions75

Bibliography76

Chapter III. Research methodology in the assessment of the implementation of the right to the best health state possible of the children and young people with HIV/AIDS in Romania.....80

3.1. Methodological framework of the research81

3.1.1. Questions, purpose and objectives of the research.....	83
3.1.2. Collection of information. Methods and techniques used.....	85
3.1.2.1. Individual interview	85
3.1.2.2. Questionnaire	90
3.1.2.3. Case study	94
3.1.3. Information analysis and interpretation.....	100
3.1.4. Theoretical and empirical aspects regarding the validity and faithfulness of the research.....	102
3.2. Ethical considerations regarding the sociological research	104
3.2.1. Ethical aspects in the research concerning the observance and exercise of the right to the best health state possible of the children and young people with HIV/AIDS in Romania	106
3.2.2. Ethical challenges in the research on children and young people with HIV/AIDS.....	111
Conclusions.....	115
Bibliography	116

**Chapter IV. Impact of the HIV infection/AIDS on the observance
and exercise of the right to the best health state possible of
seropositive children and young people in Romania119**

4.1. Stage I of the research – Results obtained following the individual interviews.....	120
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I. Comfort level ensured to children and young people with HIV/AIDS (accommodation, food, hygiene, bedsheets and equipment)	120
II. Specialists' communication with seropositive children and young people	125
III. Level of equipment and services provided.....	127
IV. Degree of information of children and young people with HIV/AIDS about their rights	129
V. Stigmatization. Discrimination.....	130
VI. Possible solutions for the optimization of the implementation of the right to the best health state possible for the children and Young people infected with HIV/AIDS.....	131
4.2. Stage II of the research	135
Results obtained following the use of questionnaires	135
Results of the quantitative research.....	136
4.3. Case studies concerning the children and Young people with HIV/AIDS	161
Conclusions of the case studies.....	193
Dissertation conclusions	194
Proposals	200
Research limits.....	201
Future research directions	203
Bibliography	204

Annexes	211
Annex I. Interview guide for children/young people with HIV/AIDS .	211
Annex II. Thematic analysis grid.....	213
Annex III. Questionnaire for specialists	214
Annex IV. Consent forms – individual interview.....	218
Annex V. Consent form – child’s legal representative	219
Annex VI. Interview guides used in conducting the case studies.....	220

Key words: HIV, AIDS, child, health, health state, good health state, right to health.

ABSTRACT

Health is currently defined as the state of a system whose organs function normally and regularly.

In 1946, the World Health Organization defined health as not only the absence of disease or disability, but as a full state of physical, mental and social wellbeing. Later, this definition included also “the capacity of leading a productive, social and economic life”. Health is considered not as an abstract state but rather as the individual’s possibility of being successful, of responding positively to environmental stimuli.

Vlădescu said that the state of health could be defined as the absence of physical pain, physical incapacity or conditions that could lead to decease, as a good emotional state, as a satisfying social position (Vlădescu, 2010:25).

According to the World Health Organization (fact. sheet no. 31:3), the right to health includes the following basic rights: the right to drinking water, the right to appropriate food, the right to an appropriate dwelling, the right to optimum environmental and work conditions, the right to information and education on health, the right to prevention, treatment and disease control, access to essential medication and basic services, the population’s right to participate in the decisions related to the health state.

HIV is the human immunodeficiency virus attacking the immune system and hindering the fight of the system against infections and diseases. The main type of cell affected by HIV is the T-helper lymphocyte. A significant decrease in the number of T-helper cells considerably weakens the immune system of the body system.

AIDS is the final form of the HIV infection, a polymorphic syndrome characterised by repeated and rebellious infections (opportunistic infections) that emerge and develop in people whose immune system is strongly affected (Usaci, 2003:19). According to Buzducea (1997:18), AIDS is an accidental social problem that cannot be completely eradicated, but the ideal is to control AIDS epidemiologically, clinically and therapeutically at the community level. According to the National Strategy for the monitoring, control and prevention of HIV/AIDS cases between 2004 and 2007, HIV/AIDS is more than a public health priority, it is a complex problem affecting all society components.

The **dissertation topic** is “*The right of HIV Infected Children and Young People to the Highest Attainable Standard of Health in Romania*”. The **general dissertation objective** is the assessment of the implementation of the right to the best health state possible in Romania of children and young people with HIV/AIDS. To meet this general objective, we set the following **specific objectives**:

O1: Identifying and analysing the legal elements that mention the right to the best health state of children and young people with HIV/AIDS;

O2: Identifying and examining the risk situations to which children and young people with HIV/AIDS can be exposed in the area of the observance and exercise of their rights;

O3: Identifying the perceptions of the children with HIV/AIDS as regards the observance of their right to the best health state possible;

O4: Identifying the perceptions of the young people with HIV/AIDS as regards the observance of their right to the best health state possible;

O5: Identifying the specialists' opinion on the right to the best health state possible of the children and young people with HIV/ AIDS in Romania.

On this line, this thesis has brought to attention a research undertaking that pursued the identification and analysis of the particularities existing in the area of the observance and exercise of the right to the best health state possible of the children and young people with HIV/ AIDS in Romania – the population included in the study being represented by children and young people with HIV/AIDS benefiting from a special protection measure – by specialists working with this category of people as well as other protectors of seropositive children and young people. The research was conceived in two different

stages, from the point of view both of the methods used and of the participants in the research.

Thus, **the first stage** of the research brought to attention the information obtained from the individual interviews of the seropositive children and young people of Iași, Constanța and Bucharest. This information regards the influence of the HIV infection/AIDS in the area of the observance of the seropositive people's rights, the factors that can contribute to the observance and exercise of the right to the highest attainable standard of health of children and young people with HIV/AIDS in Romania, the perception of children and young people with HIV/AIDS in Romania as regards the observance of their rights, the existence of a barrier in the area of the observance and exercise of rights for this category of people, as well as the existence of possible solutions for the optimization of the implementation of the right to the best health state possible for children and young people with HIV/AIDS in Romania.

The **second stage** of the research brings to attention information obtained by means of the questionnaires applied to specialists of the General Directorate for Social Work and Child Welfare of Iași, "Sf. Parascheva" Hospital for Infectious Diseases, "Sf. Maria" Pediatric Hospital of Iași, the National Union of the Organizations for People Affected by HIV/AIDS and ADV Constanța, and the reporting of a

series of case studies regarding children and young people with HIV/AIDS. Both the questionnaire-based research and the collection of information for the case studies were channelled mainly to the analysis of the observance and exercise of the right to the highest attainable standard of health of children and young people with HIV/AIDS in Romania.

The reason I chose this topic for my dissertation was the findings in my activity as a specialist in working with young people and children with HIV/AIDS residing in a social care and welfare centre. Practically, I found a large number of children and young people with HIV/AIDS unsatisfied with the observance and exercise of their right to the best health state possible.

In establishing the topic, I was also motivated by the vastness of the HIV/AIDS phenomenon in Romania and by the limited amount of research conducted in the HIV infection/ AIDS field that considered all the aspects related to the observance and exercise of the right to health.

The dissertation “The Right of HIV Infected children and Young People to the Highest Attainable Standard of Health in Romania” is structured into four chapters, as follows: **chapter I** - *Sociological perspectives on the infection with HIV/AIDS*, **chapter II** - *Socio-legal considerations regarding the right to the best health state possible of children and young people with HIV/AIDS*, **chapter III** - *Research methodology in the assessment of the implementation of the right to the*

*best health state possible of the children and young people with HIV/AIDS in Romania, **chapter IV** - Impact of the HIV infection/ AIDS on the observance and exercise of the right to the best health state possible of seropositive children and young people in Romania.*

Chapter I

The understanding of the HIV/AIDS phenomenon implies good knowledge on the general framework of conceptualization of the HIV infection-AIDS and of the implications of this disease both at individual level and at the level of the social context where it is found. To outline these aspects, the **objective** of the first chapter of the thesis is the presentation of the concepts: HIV virus, AIDS disease, the history of this epidemic, population groups exposed to the risk of being infected with HIV/ developing AIDS, psycho-social considerations on the HIV infection/ AIDS and the particular aspects of this infection in Romania. This information is outlined as a starting point for the presentation of the aspects specific to the observance and exercise of the right to the best health state possible of children and young people with HIV/AIDS in Romania. Following this presentation framework, we mention that in this research, the phenomenon of the HIV infection/ AIDS acquires a secondary significance, and it is studied only as regards its importance in relation with the circumstances of the observance and exercise of the right to the best health state possible of seropositive children and young people.

As for **chapter II** of the dissertation, it was intended for the identification, analysis and presentation of legal elements stipulating the right to the best health state possible of seropositive children and young people. To this purpose, the chapter was structured in two subchapters, one of which being dedicated to the legal framework regarding the protection of children's rights, and the second being dedicated to the presentation of legal references regarding the right to health of seropositive children and young people. Attention is drawn to the theoretical approaches that highlight the origin of the idea of children's rights in Romania, the history concerning the laws on children's rights in Romania, the children's rights from the perspective of the new sociology, the legal framework regarding the right to health of seropositive children and young people in the international and national context, as well as the social policies and programmes addressed to this category of people.

Chapter III was meant for the methodological aspects approached and the ethical dimension of the research. The first section of this chapter presents the methodological framework of the research by illustrating the methods and techniques used in collecting data, the batch of participants and the research process. The second section was dedicated to the ethical implications of the research by bringing to light the deontological considerations specific to the research in the socio-human field in general, and the ethical challenges we faced in collecting

the data in the two categories of respondents participating the research, namely seropositive children and young people, and specialists working with this category of people respectively.

In **chapter IV**, we presented the results of the research we conducted. We mention that the research was conducted in Iași County, Constanța County and Bucharest Municipality and the set purpose and objectives were met in two stages that differ from the point of view of the used methods and of the research participants.

The first research stage consisted in individual interviews of seropositive children and young people in Iași County, Constanța County and Bucharest Municipality. The topics approached in the individual interviews were: the comfort level ensured to children and young people with HIV/AIDS, specialists' communication with seropositive children and young people, provided services and the level of institutional equipment, the degree of information of the children and young people with HIV/AIDS about their rights, stigmatization – discrimination, possible solutions for the optimization of the implementation of the right to the best health state possible.

The second research stage consisted in questionnaires for specialists working with seropositive children and young people in Iași County, Constanța County and Bucharest Municipality. The questionnaire included six topics of interest for the research: the comfort

level ensured to children and young people with HIV/AIDS, the level of institutional equipment and services provided, specialists' communication with children and young people with HIV/ AIDS, the degree of information of the children and young people with HIV/AIDS about their rights, stigmatization, the degree of development of the complementary non-medical methods of attending to children and young people with HIV/AIDS, and the specialists' opinion related to the socio-professional status and the working environment.

As for the subject of *the comfort level ensured to seropositive children and young people*, the answers of the interviewees point out the fact that, according to their perception, the living conditions at the time of the research are optimum, and this definitely influences the maintenance of their health state.

The participants in the research highlighted that the living premises were appropriately cleaned by both employees and beneficiaries. According to *law no. 584/2002 on the measures of preventing and fighting against the spread of AIDS in Romania* and of protecting HIV-infected people, adequate food contributes to the efficiency of the antiretroviral treatment and implicitly to the maintenance of the health state of people with HIV/AIDS.

Inappropriate food significantly compromises the capacity of the body system of fighting against the disease and generates risks in human

development and survival. The interviewed children and young people as well as specialists who participated in the questionnaire-based stage consider that they receive food that is adequate from the quantitative and qualitative point of view, but part of the additional allowance is spent on vices, of which mostly tobacco and alcohol consumption.

The interviewed children and young people own goods and bedding, but they are sometimes unsatisfied by their quality and quantity (they are limited by the allotted budget).

As regards the *specialists' communication with seropositive children and young people*, we can say this subject was submitted to analysis to the purpose of highlighting the particularities of the observance of the right to the best health state of seropositive children and young people, because the essential element in decision-making regarding health is interpersonal communication.

The conclusion we draw from the answers of the seropositive children and young people and of the specialists is that the need and demand of correct and relevant information related to their health state are increasing, the communication between people with HIV/AIDS and specialists needs constant improvement, and people with HIV/AIDS need clear information that they can understand and constant encouraging messages.

The exploration of the subject *the level of equipment and services provided* confirms that the interviewed young people and children are registered with a family physician, benefit from medical

care offered by the physician and nurse from their institution and by the infectious disease specialist, but they are also affected by law infringements in obtaining free medication, though the gratuity of the medication for this category of people is stipulated by the law (art. 10, law 448/2006). According to art. 10 of law 584/2002, antiretroviral medication and medication for diseases associated with the HIV infection/AIDS are administrated free of charge according to the Therapeutic Guide of the National Committee for the Monitoring, Control and Prevention of the HIV/AIDS Cases, during the entire period necessary, based on the National Programme for HIV/ AIDS Monitoring and Control.

Both seropositive children and young people and specialists say that they dealt with interruptions in the supply and administration of antiretroviral treatment. These interruptions in the supply of antiretroviral medication show that seropositive people deal with problems related to the violation of their right to health and even the violation of their right to life.

We approached the subject *the degree of information of children and young people with HIV/AIDS about their rights* in order to analyse the extent to which the seropositive children and young people participating in the research are informed about their rights. Knowing their rights, seropositive children and young people will be able to claim them and will take action for the observance of their rights and other people's rights.

The exploration of the subject *the degree of information of children and young people with HIV/AIDS about their rights* confirms the fact that both seropositive children and young people know their rights, but they would hold more information about their rights if they used socialization networks (Facebook, Twitter, internet blogs), if they participated in peer-education activities, if they created groups or organizations with leaders in the planning, implementation and assessment of services. In July 2014, the World Health Organization considered that the peer-education activities are strategically successful in improving knowledge about the HIV, testing, counselling, care of young people with HIV. The information obtained is more important if provided in the places attended by key populations (dance and music festivals, rock concerts, cultural gatherings).

The participants in the research show that there are situations when their right to information is violated due to the lack of provision of information or the inappropriate provision of information related to their health state, diagnosis, treatment and disease prognostic.

We chose to analyse the subject *stigmatisation – discrimination* as it is generally recognised that the HIV/AIDS raises many problems related to the human rights. Therefore, the protection and support of human rights are essential in preventing the HIV transmission and the reduction of the impact of the HIV/AIDS on many lives. Many of the human rights are relevant in the context of the HIV infection/AIDS, such as the right of not being a victim to stigmatization and discrimination.

The exploration of this subject confirms that stigmatization and discrimination are present among seropositive children and young people in the healthcare field and can take different shapes such as postponement, refusal, overprotection. According to the World Health Organization, the connection between the HIV/AIDS pandemic and stigmatization and discrimination is recognised. The discrimination of seropositive children and young people makes them more vulnerable to contacting the virus. The fear of being diagnosed as seropositive can prevent them from asking for counselling, diagnosis or treatment. An important component of the right to health of seropositive people is the universal access to treatment and medical care.

It is important that all medical services be available for this category of people according to art. 9, law 584/2002.

We chose to analyse the subject *possible solutions for the optimization of the implementation of the right to the best health state possible for children and young people with HIV/AIDS* because we considered that healthcare programmes are more efficient and have a positive impact on the health state when the affected population takes part in their development.

The second research stage involved six case studies on children and young people with HIV/AIDS in Romania. We conducted the case studies to complete the information picture in respect to the observance of the rights of seropositive people, with an emphasis on the analysis of the observance and exercise of their right to health.

I found violations of rights in the studied cases: the children's right to be raised and attended by both parents (because of the health state of seropositive parents and/or children, of the decease of on the parents, of their precarious financial situation and because of the lack of supportive people), the children's right to education (oriented to special education in four of the six studied cases), the right to health (interruptions in the administration of antiretroviral treatment, postponements, delays, refusal of providing specialized medical services, purchasing certain medication on their own expense).

In conclusion, to prevent risk situations to which seropositive children and young people can be exposed in the area of the observance and exercise of their right to health, the research participants consider necessary the continuous and high quality professional training of the providers of medical care to people with HIV/AIDS, the forbiddance of discrimination for reasons related to the health state, higher sanctions for discriminating and stigmatizing people, the existence of policies and procedures allowing people to report the violation of their rights, universal continuous and non-discriminating access to the prevention, treatment and medical care services based on the improvement of the management activity in the supply and distribution of medication specific to the HIV/AIDS and opportunistic infections.

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