

Motto

*“The man is always both: mendicant and prince,
and is unilateral and not a whole,
as long as he/she did not achieve on its own both.
The mission of man is to be prince, his/her own master,
but at the same time he/she is a mendicant,
who must live with what destiny dispenses.”*

Thorwald Dethlefsen - Ödipus der Rätsellöser

Participation or exclusion of HIV infected children in Romania
- from vulnerability to empowerment -

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Abstract

One of the most important unsolved social issues in Romania is the situation of HIV infected children. Romania has a large group of children living with HIV and AIDS, over 7,000, according to the latest epidemiological data. All this children/teenagers who are now turning to young adults were infected between 1987 and 1991 by unscreened blood transfusions and blood products, not properly sterilized needles, injections, surgical interventions etc. We would like to add that this is a unique, exceptional situation as they are the largest such group in Europe.

Troublesome questions arise regarding participation or exclusion of young people living with HIV infection (YPLHIV) in Romania: how much discrimination, victimization are YPLHIV experiencing?; what is their level of education – do they have access to appropriate training and employment?; is Romania prepared to further guarantee to YPLHIV specific social protection; and how do YPLHIV cope with adulthood perspectives on individual, family and social level?. These questions are answered based on latest HIV/AIDS related data and they are exemplified with our personal and professional experiences from working with HIV infected children and their affected families.

Introduction - international outlook

HIV infection/AIDS is still a major public issue worldwide. It is estimated that every day 5,500 persons are dying because of HIV/AIDS across the globe, meaning that

every 15 seconds somebody's life is taken by HIV/AIDS. Children and parents are actually a vulnerable group as data show that next year, in 2010, almost 25 million children will have lost one or both parents due to HIV/AIDS (USAID, 2009).

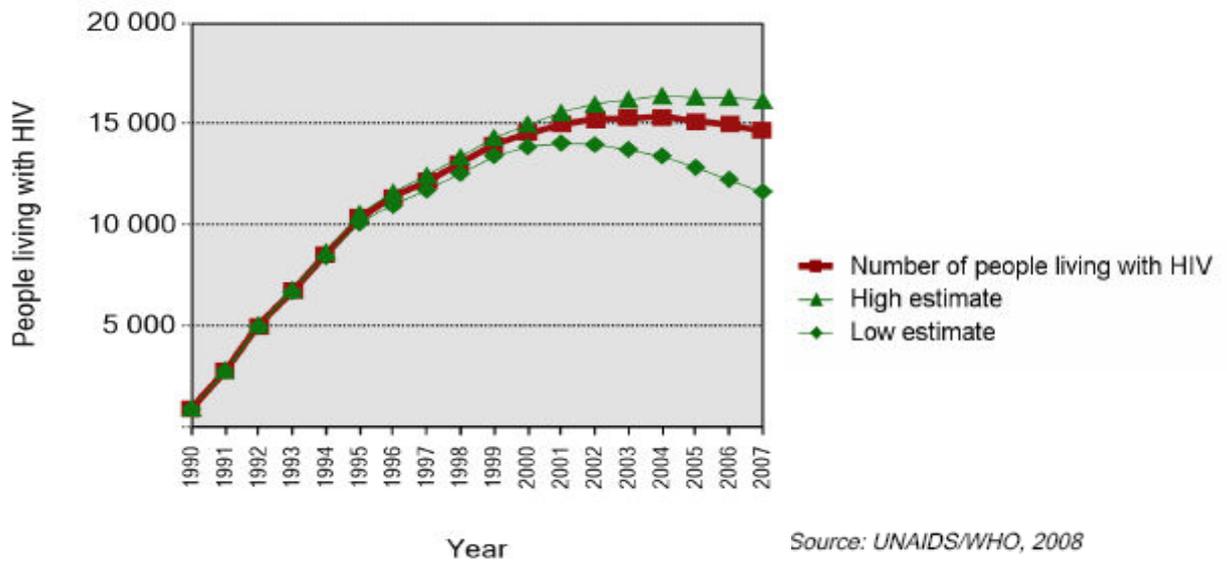
Moreover there is evidence that transmission of HIV infection has been increasing in Europe in the last years. According to a recent report issued by the European Center for Disease Prevention and Control (ECDC) and the World Health Organization (WHO) in the European Region rate of HIV infection nearly doubled from 2000 to 2007, one of the most at-risk countries being Moldova, our neighbor country (ECDC & WHO, 2008).

Overview of the HIV/AIDS epidemic in Romania

World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) reported that in 2007 the average number of people living with HIV/AIDS in Romania was 15,000 (*Figure 1.*) (UNGASS, 2008). Among them there are more than 7,000 children and youth who were infected in hospitals and care institutions (e.g. orphanages) when transfusions were done using unscreened blood and needles for vaccination were reused. In several reports they are called "Romania's miracle children" because they are survivors from at least 10,000 children infected in the medical system during 1987-1991. They are all victims of the former, low-quality Romanian health care system and of medical malpraxis. Here it should be underscored that the Romanian health care system never admitted or took responsibility for this „mistake”, which affects more than 200 young children's life only in Mures County, where Benone Association is active.

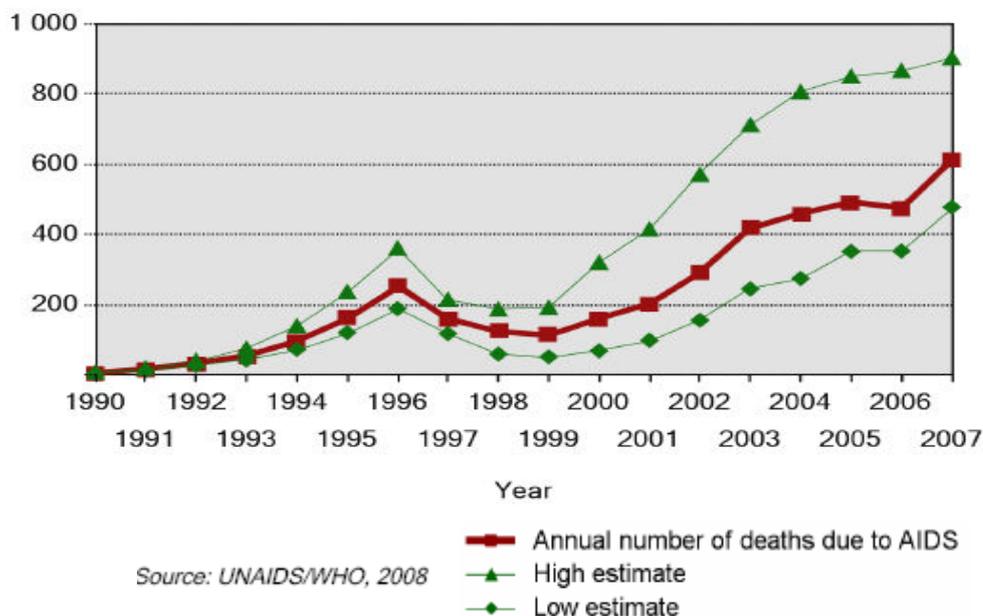
Unfortunately around 80% of children living with HIV/AIDS in Romania (approximately 5,600 cases) have not been told about their medical status. On the one hand it can be explained by fear of constant discrimination and on the other hand it is related to the Romanian law. Under this, children do not have automatic right to be informed, unless parents consent to it. Less than 20% of affected Romanian parents do consent for diagnosis disclosure (Ionescu, 2006) which negatively impacts medical and psychosocial therapy/counseling of HIV+ children/youth and also their education, employment, social-sexual life.

Figure 1. Number of people living with HIV/AIDS in Romania – trends



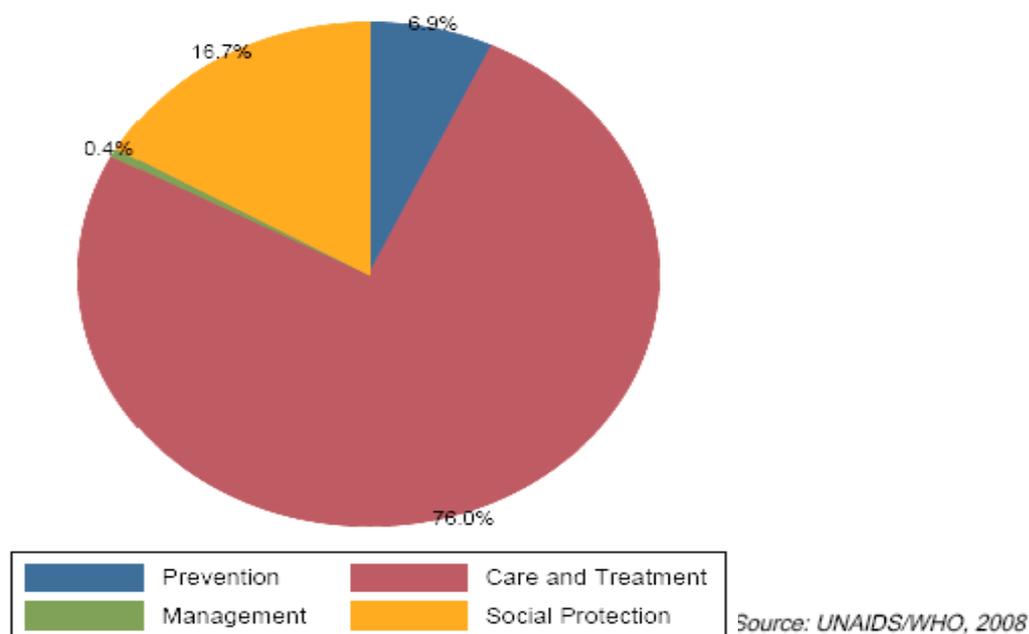
In 2007 almost 600 persons died because of AIDS in Romania, less than 5% of persons infected with HIV (Figure 2.) (UNGASS, 2008). This relatively low AIDS mortality rate is most surely connected with universal access to antiretroviral therapy. In 2001 Romania developed a National HIV Treatment Protocol for Universal Access to Treatment and Care (Law 584/2002), which at that time actually was the first such helpful, life saving initiative in Eastern Europe. Now antiretroviral therapy coverage in Romania is 73% (UNGASS, 2008).

Figure 2. Number of deaths due to AIDS in Romania – trends



Although access to HAART (highly active antiretroviral therapy) treatment can be considered universal in Romania and there is a strong governmental commitment to it, HIV/AIDS prevention is still very limited. Latest data on distribution of HIV/AIDS related expenditures in Romania shows that 92,7% of finances are spent on care/treatment and social protection and less than 7% on HIV/AIDS prevention (*Figure 3.*) (UNGASS, 2008). It is worth mentioning that in Romania there is no specific nationwide HIV/AIDS prevention program, this is included only in part in the optional national health education curricula (overall 32 hours / semester).

Figure 3. Distribution of HIV/AIDS related expenditures in Romania



Major challenges and national responses

We will highlight and detail four major problems faced nowadays by young people living with HIV/AIDS in Romania: significant discrimination, low education, lack of vocational/professional integration and incomplete social protection.

A national representative study conducted by Soros Foundation Romania showed that 42% of Romanians would dislike having an HIV infected neighbor. This social distance rate has been increasing from 2005 when it was 37% to 42% in 2007 (Bădescu, Comșa, Sandu & Stănculescu, 2007). Discrimination negatively influences

access of YPLHIV to education, medical and psychosocial care and reduces their employment odds. Discrimination against young people living with HIV/AIDS is the highest in the medical (47,5%) and social care (27,5%) system. According to UNOPA monitoring data in 2008 almost half of YPLHIV in Romania faced discrimination in access to necessary medical services, especially dental (28.0%) and emergency care. Most frequently their right to privacy and confidentiality is victimized but usually there are no effective and appropriate sanctions for this type of discrimination. UNOPA, the national umbrella organization of associations/foundations representing the rights of HIV+ people in Romania carries out monitoring activities four times each year. Main purpose of monitoring the rights of children living with HIV/AIDS is fighting discrimination, stigma and social segregation. Monitoring in Mures County was done by Benone Association.

Although access of young people living with HIV/AIDS to all forms of education is guaranteed by law in Romania, based on monitoring data 41,2% of YPLHIV (15-19 age group) had already abandoned school and 9% never went to school. From those who attended school, 24.3% graduated primary and 48.9% secondary school (UNOPA, 2009). We need to ensure appropriate education for the needs of YPLHIV, which in turn would give them necessary support to become productive, integrated adult members of the Romanian society.

Furthermore both NGOs and public authorities know little about vocational training, tutoring services and especially professional integration of young people living with HIV/AIDS in Romania. The lack of tutoring, of professional trainings, courses, studies, lack of jobs, and the very limited areas where they can work without being discriminated or stigmatized is a major challenge for the future. According to UNOPA study - „From vulnerability to empowerment - HIV/AIDS and employment” (2009) less than 1% of employers admitted that they have employed HIV+ persons. 61% declared that they do not have employees living with HIV/AIDS and 38% of them do not know if they have HIV+ employees or not. Need for similar studies is urgent because this way we could fight public intolerance, lack of knowledge, and also we can influence public opinion, by educating, offering prevention programs, and any additional information which encourages lobby, advocacy, awareness, responsiveness, and consciousness.

Finally more than 7,000 children living with HIV/AIDS in Romania are aging out of the existing social protection system, guaranteed by Law 448/2006 and there is no real plan for what will happen with them, especially with the most vulnerable groups, HIV-positive children who are clients of child protection services. Because there is a clear need to improve the social protection system, and to make steps for the integration of this YPLWHA (Young People Living with HIV/AIDS), many national, regional and international federations, organizations and associations cooperated and organized fund raising, charity events, and programs for lobby and advocacy in HIV/AIDS related issues.

Case study - Benone Association

Benone Association was founded in 2001 by parents, whose children were infected with HIV in Targu Mures, Romania. The president and vice-president of Benone Association are also mothers, whose children had been infected with HIV. Since 2002 Benone Association is member of the National Union of the Association of People Affected by HIV/AIDS (UNOPA) and of the „Fighters” Network.

The “Fighters” network was established by HIV infected children and youth, because they wanted to prove that they have the same problems, responsibilities and rights as their non-infected peers. They organized a lot of courses, trainings, and meetings for young people living with HIV/AIDS and one of their most valuable results is the “Positive” journal. This journal proposes to educate general public and local communities about HIV/AIDS, about needs and problems of YPLHIV and also it is trying to eliminate discrimination. Members of the “Fighters” network aim to demonstrate that they grow up and they have the necessary resources to become active participants in our society.

The mission of Benone Association is to protect and promote the rights of PLWHA (People Living with HIV/AIDS) and to improve their quality of life, as this is a chronic condition without real perspectives for cure. Main objectives: to provide social, psychological, juridical support to people infected with and affected by HIV/AIDS; to promote tolerance and non-discrimination towards HIV+ people and to prevent the spread of HIV/AIDS, a second epidemical wave. We are aware that this

large group of HIV+ youth in Romania provides a unique opportunity for active participation in prevention and in fighting against stigma and discrimination.

This article also shortly focuses on our personal and professional experiences gained from working with HIV infected children and their affected families at Benone Association. Our main objectives were to reduce psychosocial vulnerability, discrimination and to improve social and community involvement of HIV infected children through teambuilding, communication training and empowerment. They can not assume their disease, because the community they live in mostly doesn't accept this. So they have to be quiet, especially in small cities, where everybody knows everybody. Sometimes they can only find understanding in the help group where they don't have to keep this "secret". This short description of our activities with HIV+ children and their families will reflect circumstantialities of our work.

President of Benone Association asked us to start supportive group activities back in 2002. At first there were 12 members, 6 children and their mothers. 8 of them were living in Targu Mures city, and 4 of them were from the countryside. When we started group activities, together we all realized that besides political and social advocacy, infected children and their parents need to have a better psychological, social and familial well-being and also they need to strengthen their participation in the local community. Our supportive groups are based on the following elements:

- self-help techniques
- communication skills development
- empowerment and mutual / peer support
- stress reduction activities and exercises (e.g. progressive relaxation training)

After three meetings with this group we started to have relevant information about family relations and about such normative developmental tasks/crisis as autonomy for adolescents. Maria, one of the mothers told us: "They would like to become independent persons but even now, I cannot accept this, because I cannot find my place. I am shutting the door but I feel a pain." Kati added that she would like to rearrange the relationship with her son: "I would like to love him, the way I love my other, non-infected child". Her husband is alcoholic and disabled. They don't have intimate relationship anymore and she is still sleeping in the same bed with her 14 years old

child. Ibi remembers all of us that it is very important to have a good communication in the family, to be patient with family members - she explained: "Every time when we would like to enter in our girl's room, we are knocking on the door."

One of the most important elements in our group activities is working with family pictures method. This time I will shortly present working with Maria's family pictures. On the first picture there was the family and the one year old healthy child: "He was a crying child, he cried 22 hours in a day. He had long hair. He was very fragile. He got a lot of injections. He lived one week with injections and the other one without injections and so on". On the second picture there was the child with his sister. "On the third picture you can see that our child is ill. After 1989, when we have found out that he is infected, we didn't celebrate his birthday anymore. In 1999 I decided, that we have to restart family life, because we were crashed. My husband became alcoholic and absent"-said Maria related to this picture. The next picture was made on 22nd of December, 2000, before Christmas, when her son had 41 grade fevers, and she prayed to God to keep him alive. "My son was very ill, he didn't want to live, and he asked the nurses to put poison in his food. The doctor told me he doesn't have chances to live any longer. I started to buy grave place, but after a few moments I said to myself that my son is still living and I will not organize his funeral. Now I can tell you that we are fine, actually we are preparing to have final graduation exams next year" – says Maria showing the last picture.

Today we are still organizing group activities for HIV+ young adults and their families and in the future we would like to encourage husbands/fathers, brothers and sisters, and also healthy peers to work with us.

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medical, educational and social situation/participation of young people living with HIV/AIDS in Romania.

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