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UKRAINIAN AIDS CENTRE, MINISTRY OF HEALTH OF UKRAINE

CHILDREN AND YOUNG PEOPLE
AFFECTED BY HIV/AIDS
IN UKRAINE
THEMATIC STUDY

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HIV infection among children: dynamics, diagnostics, regional features, and children vulnerable to HIV infection

The second stage of HIV spread in Ukraine involved epidemic processes in children population.

The main route of younger children infection is virus transmission from HIV+ mother during pregnancy, delivery or breast-feeding.

In summer 2001 the Ukrainian AIDS Centre at the Ministry of Health of Ukraine supported by UNICEF conducted a special thematic study aimed at assessing HIV/AIDS prevalence among children in regions of Ukraine and at identifying weak points in operating epidemiological monitoring system. Regions with varying epidemic situations were identified for carrying it out. Not only epidemiological, but also social and medical aspects of the problem were looked into in the regions. The researchers have developed a questionnaire containing questions not stipulated by statistical forms currently in use.

The status of 746 children has been subject to analysis, with 722 of them born from HIV-positive mothers and 24 children infected through injecting drug use. The regional break-up of the surveyed children was as follows: Dnipropetrovsk region – 366 children, Mykolayiv region – 261, Kherson region – 42, the city of Sevastopol – 33, Cherkasy region – 28, and Ivano-Frankivsk region – 9.

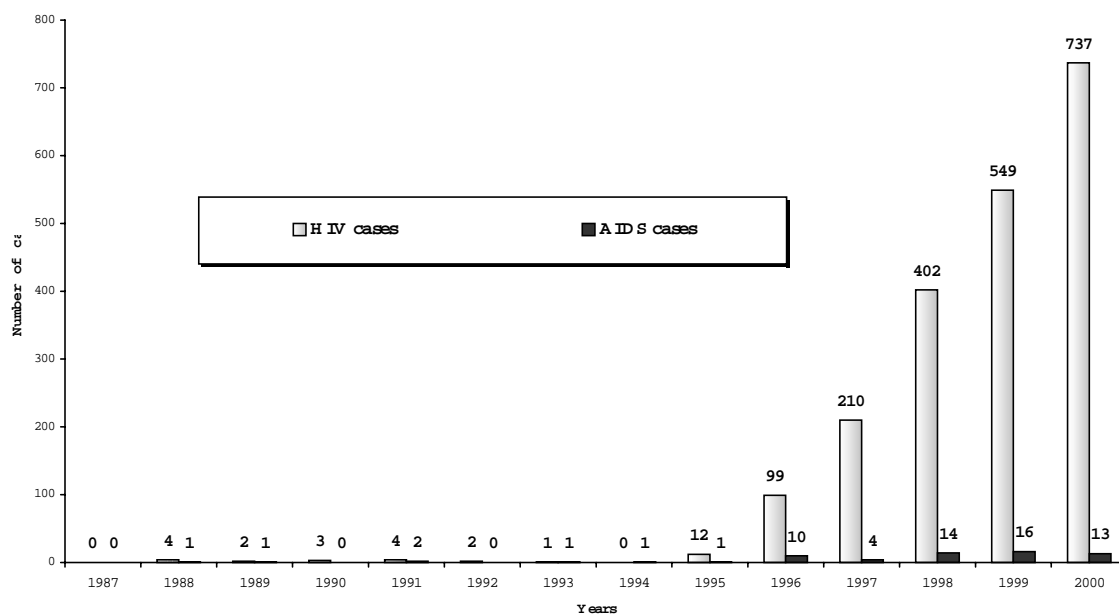
Children break-up by age was as follows: under one year inclusive – 27.6 %, under two years – 28.4 % under three years – 19.2 %, under four – 13.5 %, under five – 5.8 %, under six – 2.1 %, under seven – 0.6 %, over seven – 2.8 %.

The next outburst of HIV infection hits the adolescents, especially children with loosened family ties and inadequate life skills where a considerable portion of school age children belongs, as well as street children, children that are deprived of parental care and are placed into public care. The major routes of HIV infection in this group are parenteral (through injecting drug use) and sexual. Injecting drug use, early beginning of and carelessness in sex life represent behavioural models that can result in broader epidemic spread among these groups, even further enhanced by pauperization among considerable portion of population.

1.2.1. Dynamics and regional break-up of HIV positive children, HIV infection diagnostics in children

HIV spread among Ukrainian children started in 1995, when the second stage in epidemic development began. Dynamics in registered HIV+ children and children with AIDS provides evidence that there is need for immediate and energetic preventive measures to be taken by all stakeholders (Fig.4).

Fig. 4. Dynamics in registered HIV/AIDS cases among children in Ukraine



The greatest number of HIV positive children is concentrated in the regions with maximum HIV prevalence levels: Odessa, Dnipropetrovsk, Donetsk, and Mykolaiv regions and the Autonomous Republic of Crimea.

As of January 1, 2002, the number of children born from HIV positive mothers exceeded 2,962 persons. Their actual number, however, is smaller, since over 1,500 children are under supervision until the diagnosis is specified.

Final diagnosis regarding a child's HIV status in case the child was born from a HIV positive mother is only possible, relying upon current diagnostics methods, after 18 months since the child's birth when mother's antibodies disappear and the final testing is conducted.

Since identifying the HIV status of a child born from HIV positive mother affects her/his future destiny, there is a need to shift to methods enabling diagnosing HIV infection immediately after the child is born. This is, in particular, the method of polymerase chain reaction that is scheduled for implementation in Ukraine's treatment and prevention institutions in accordance with the Ministry of Health Program "Preventing HIV Transmission from Mother to Child for Years 2001-2003".

Timely refutation (or corroboration) of HIV diagnosis in children born from HIV positive mothers is also complicated considerably by problems arising in connection with testing residents of rayon centres and remote towns and villages; with virtual absence of epidemiological monitoring over children; and with some parents' unwillingness to lose social allowance provided for a HIV positive child's maintenance on monthly basis.

1.2.2. Younger HIV positive children

The examination conducted by the Ukrainian AIDS Centre in summer 2001 that covered 722 children born from HIV positive mothers with confirmed HIV positive

status established that nearly 100 percent of these children were infected through *virus transmission from mother to child*.

Age characteristics of surveyed children are as follows: under 1 year - 28%, under 2 – 28%, under 3 – 19%, under 4 – 14%, under 5 – 6%, under 6 – 2%, under 7 – 1%, over 7 – 3%.

Overwhelming majority of children (80%) live with their biological families. The overwhelming majority of children (88%) living in the families live with parents (one or two). 10% live with other relatives and 2% were adopted. Among children living in family environment, 60% live in complete families, the rest – in incomplete ones. At the moment when the questionnaire was filled in, employed parents constituted 52%, the rest were not employed. The overwhelming majority of mothers (72%) were not employed.

At the moment of examination almost 20% of children were in public care or medical institutions.

There were no cases recorded among HIV infected children of placing HIV+ children into a foster family care or to a family-type children’s home.

Cases were registered of both national and international adoptions of children born from HIV positive mothers with unconfirmed diagnosis. Additional survey was conducted aimed at in-depth study of social and material status of families with HIV positive children in four regions of Ukraine (Ivano-Frankivsk, Mykolayiv, Kherson and Cherkasy regions).

It was established that 70% of children (243 □ 347) were born in dysfunctional families (Table3). Every fifth child was abandoned by her/his mother at the maternity hospital. Every tenth child was raised in the family where one or both parents were alcohol addicts, IDU, beggars or were convicted. Virtually in all surveyed families parents, too, were HIV positive.

□□□□. **2. Social status of families with perinatally infected HIV+ children, Ivano-Frankivsk, Mykolayiv, Kherson and Cherkasy regions.**

<i>Regions</i>	<i>Family</i>				
	<i>Total</i>	<i>Adequate social status</i>		<i>Inadequate social status</i>	
		<i>Absolute number</i>	<i>%</i>	<i>Absolute number</i>	<i>%</i>
Ivano-Frankivsk	9	4	44	5	56
Mykolayiv	262	68	26	194	74
Kherson	48	22	45	26	55
Cherkasy	28	10	36	18	64
Total	347	104	30	243	70

Almost 85% of parents in surveyed dysfunctional families with HIV positive children are young people aged under 30. 65% of women and 35% of men belong to age group 18 - 25.

In some cases children only formally can be said to “live” in these families, since parents (IDU in particular) would place their children in infant homes for a certain period, subsequently taking her/him back to the family. In other cases parents are temporarily deprived of parental rights for a certain period for reasons related to their asocial behaviours, with children also placed into infant homes on temporary basis.

The findings showed that material provision for children was low or very low in 82% of all families and did not always correlate with the families’ social status.

Only every fifth family with adequate social status had an opportunity to provide their child with appropriate nutrition, necessary implements, books, toys, etc. These children’s parents tended to have secondary technical education or college degrees and were employed. Still, about 40% of “normal” families required additional material resources, relied upon their relations’ assistance or took additional jobs. About 60% of such families were in no position to satisfy the child’s needs.

In families with inadequate social status, typically, even children’s fundamental needs were not satisfied.

To sum up,

- ***The majority of HIV positive children (80%) live in their biological families***
- ***Every fifth HIV positive child has been abandoned by her/his parents and is placed to a public care or medical residential institution***
- ***70% families with HIV positive children belong to dysfunctional families, which do not satisfy even fundamental child’s needs in food and provide no conditions for the child’s normal development.***
- ***The needs of children living in “normal” families are also not fully satisfied. 40% of such families have low incomes.***
- ***Almost 85% of parents in surveyed dysfunctional families with HIV positive children are young people aged under 30. 65% of women and 35% of men belong to age group 18 – 25.***
- ***Not a single case was registered among all HIV infected children of a HIV positive child placement into a foster family or to a family-type children’s home.***

Mother to Child HIV transmission

Research conducted by the Ukrainian AIDS Centre at the Ministry of Health of Ukraine showed also that every fifth woman from a dysfunctional family actually abandoned her child. In fact, the share of women who abandon the child forever (or for indetermined period) is much lower. They have their children institutionalized from time to time, when parents lack money for keeping them, and then take them back again.

Families with children infected with HIV by their HIV positive mothers typically comprise risk groups representatives. *A considerable portion of such women are socially isolated, they avoid contacts with government agencies, do not visit Prenatal Care Centres and seek medical assistance directly for delivery.* Pregnant women-IDU undergo abortions more rarely than “normal women”. This can be accounted for both by their social isolation, and by irresponsible attitude to their own and their future child’s health. Of 53 female sex workers examined in 2000 in Donetsk every second women had sexually transmitted diseases, five women had HIV, syphilis and hepatitis □ – all these together, seven women were HIV infected. At the same time, all the women were sure they were absolutely healthy¹.

Nevertheless, this description of risk group mothers is not exactly correct. For example, focus-groups among HIV positive drug users conducted by “Medecins sans frontiers” in spring 2000 demonstrated that some of the surveyed HIV positive IDU women would like to have children and were interested in information about the risk of HIV transmission to future children.

- 1. Available data testify to HIV epidemic seepage to women not belonging to risk groups (increasing share of virus sexual transmission).**
 - 2. The overwhelming majority of HIV positive pregnant women (65%) are young women aged under 25.**
 - 3. Most children (70%) born from HIV-positive mothers come from socially vulnerable families comprising risk groups representatives. A considerable portion of mothers in this group do not give adequate attention to their own health and to their future child’s health, and are unaware about HIV vertical transmission risk.**
 - 4. Nevertheless, every third child was born in a “normal” family which signalizes the need for awareness-raising and preventive activities among all reproductive age women, first and foremost, among pregnant women.**
 - 5. HIV transmission from mother to child awareness and attitude towards HIV positive women on the part of medical staff require appropriate attention on part of both the government and international organizations.**
 - 6. Incorporating training courses in preventing HIV transmission from mother to child and HIV infected children care into the curricula of medical educational establishments and professional upgrading courses, developing relevant**
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training materials are necessary for successful implementation of the Programme for preventing HIV transmission from mother to child in Ukraine .

□□□. Care and support for children and young people living with HIV/AIDS

A serious challenge for the government is presented by social, financial and psychological problems faced by HIV positive children, young people and their families in the context of HIV/AIDS epidemic trends in Ukraine.

3.1. Public institutions providing care and support services for HIV positive children, young people and their families

3.1.1. Service provision and their adequacy to target groups needs

Under acting legal and regulatory documents, in particular, Ministry of Health Order # 120 of May 25, 2000 and Ministry of Health Programme “Preventing HIV transmission from mother to child for years 2001-2003”, *public health care and social assistance bodies should provide the following services to HIV positive children and young people:*

With regard to treatment:

- *Set up specialized wards in children infectious disease hospitals, Drug Addiction Prevention and Treatment Centres and tuberculosis prevention and treatment centres.*

With regard to prevention and care:

- *Supply prevention and treatment institutions with antiretroviral medications for HIV prevention in newborns.*
- *Provide vaccination to HIV positive children according to schedule.*
- *Conduct clinical supervision in AIDS Centres’ clinical departments, polyclinics’ infectious diseases divisions, or, in case there are no such divisions, the supervision should be conducted by district general practitioner or pediatrician, or by children infectious diseases specialist working at in-patient clinic.*
- *If an AIDS Prevention Centre has a clinic, it is advisable to have the supervision conducted by a physician working at this clinic.*

With regard to health restoration:

- *Provide treatment to HIV positive children on annual basis at local sanatoria and spas.*

With regard to psychological support:

- *If a HIV positive child is staying at a hospital or close-type children’s institution it is advisable to invite psychologists and psychiatrists to provide appropriate psychological support.*
- *Provisions are made for medical staff appropriate training and for educating the teaching faculty working at children’s pre-schools and schools about HIV/AIDS-related issues, and about specific features involved in HIV infected children’s attendance of children’s institutions.*

With regard to social assistance:

- *Families with HIV infected children receive monthly allowance of 34 UAH.*

The following groups of children, young people and adults need services and supervision provided by public institutions:

- *Young children with HIV infection (or a suspicion of it), who for certain reasons were deprived of parental care and are placed (or should be placed) into children's homes.*
- *Families with young and school age HIV infected children.*
- *HIV positive mothers rearing HIV infected children.*
- *HIV infected children and adolescents who are injecting drug users or belong to other risk groups ("street children", children in sex business).*

Taking into account the fact that various groups of HIV infected or HIV threatened children and young people are confronted with different problems, it is obvious that ***the scope and nature of services declared by the state is not adequate to actual needs of relevant populations:***

1. *There is no system in place for providing social supervision and sociopsychological assistance to families with HIV positive children. Currently there is even no adequate monitoring over HIV positive children. Data can only be obtained through individual surveys.*
2. *There are no additional activities or assistance envisaged for HIV positive mothers.*
3. *Psychological support programmes for children and families living with HIV/AIDS that would be tailor-made to meet the needs of various age groups have not been designed yet.*
4. *The mechanism of providing conventional medical services to HIV infected children and young people has not been appropriately established, including immunization, opportunistic infections prevention, etc.*
5. *The main problem to be addressed is antiretroviral therapy.*
6. *Another problem is supplying HIV positive children with adequate feeding.*
7. *In many regions of Ukraine the placement of HIV positive children deprived of parental care has not been properly addressed yet.*
8. *The same holds true of HIV positive children's attendance of children's institutions – the fact that bars access to education to such children.*
9. *The problem of HIV positive children adoption and transfer into foster families care is not settled and requires not only legal support, but also additional administrative and organizational activities and massive information campaign promoting each child's right to be raised in a family environment.*

The scope and nature of services provided by the state and targeted at all groups of HIV positive children and young people do not correspond to those declared in government legal and regulatory documents.

The research conducted by the Ukrainian AIDS Centre at the Ministry of Health of Ukraine revealed that *only 77%* of HIV positive children have been subject to immunization required at their age, in *8%* of children actual immunization dates did not comply with the immunization schedule, while *15%* have not undergone any immunization at all.

Even though HIV positive children are entitled to annual free sanatorium/spa treatment, *not a single case was recorded of this right being exercised.*

No data is available enabling the analysis of quality and adequacy of public services and assistance provided to HIV positive children from risk groups.

3.1.2. Service provision to HIV positive children in public care institutions.

The following services have been declared as being provided by public care institutions to HIV positive children abandoned by their parents:

Stage I. Children born from HIV positive mothers are kept at the maternity hospital, or at infectious disease or somatic in-patient ward at a children's hospital.

Stage II. Until the age of four children deprived of parental care stay at infant homes run by the Ministry of Health of Ukraine.

Stage III. When a child reaches the age of four, (s)he is transferred to a children's home and then to a boarding home run by the Ministry of Education and Science of Ukraine.

According to the survey conducted by the Ukrainian AIDS Centre at the Ministry of Health of Ukraine, ***actual practice of providing services with regard to HIV positive care and treatment differs substantially from the provisions declared by government programmes, presidential decrees and departmental directives /recommendations, in particular:***

1. According to the regional data provided mainly by Chief Physicians of AIDS Centres, a child with antibodies to HIV deprived of parental care would, typically, stay for a long time either at the same (maternity) hospital where the antibodies have been detected, or at the infectious diseases or somatic ward of a children's hospital. The reason it happens is the lack of uniform national mechanism for transferring this category of children to public care bodies. *The time frame for transferring children born from HIV positive mothers, deprived of parental care and not requiring specialized treatment, from in-patient hospital wards to infant homes is not specified in regulatory documents.*

2. In case HIV infection is confirmed, a child staying at the infant home at the moment when (s)he reaches the age of four – four and a half, would most typically remain at the same home. Many cases have been recorded when children's homes refused to accept such children (in particular, in Odessa and Odessa region). Some children have been repeatedly "returned" from a children's to infant home. *It still happens in spite of acting provision stipulating obligatory transfer of children who have reached that age (regardless of their HIV status) from infant homes run by the Ministry of Health to children's homes run by Ministry of Education and Science.*

3. Even worse is the situation when a child actually lives at a hospital only because (s)he has antibodies to HIV; the hospital then is forced to perform the function of a social shelter. In some cases children spend three or four years at hospitals.

To sum up, Ukrainian children born from HIV infected mothers and children with confirmed HIV infection deprived of parental care are placed at infant homes (Odessa, Dnipropetrovsk, Cherkasy, Donetsk) or at infectious disease or somatic hospital wards.

This situation gives rise to the following adverse effects:

- Children's retarded development since the hospitals lack necessary educational facilities. This situation *violates Article 5 of the Convention on the Rights of the Child declaring the state's duty to govern the child in a manner consistent with the evolving capacities of the child, as well as the child's right to education (Article 28 of the Convention).*
- Failure to keep confidential medical information about such children when they are transferred from one institution to another.
- Refusal to accept HIV positive children at institutions run by the Ministry of Education and their "return" to infant homes result in keeping HIV infected children aged 5-6 in the same groups with newly arrived infants with non-established diagnoses, creating inadmissible conditions for children keeping and threatening HIV initial infection and reinfection in children born from HIV positive mothers.
- Some experts believe that if the current system for transferring children deprived of parental rights from one institution to another persists (infant home-children's home-boarding school), HIV positive children would both keep dying from opportunistic infections, and would receive serious psychological shocks due to stigmatizing and discrimination caused by making public their HIV status, which is a common phenomenon.
- HIV positive children in public care institutions are deprived of the possibility to be subjected to antiretroviral therapy in the same way, as children living in families. It means that they are doomed to inevitable death.

There are no uniform recommendations in place with regard to HIV infected children care and treatment, *which runs contrary to Article 20 of the Convention on the Rights of the Child, and prevents the state from meeting its responsibility regarding primary consideration to the child's best interests (Article 3 of the Convention)*

Conclusions to Subsection

- 1. Review of HIV positive children status in public care institutions gives grounds to argue that there are numerous cases of non-conformity to Articles 3, 5, 20 and 28 of the Convention on the Rights of the Child.***

2. *To improve the situation, it is necessary to put in place a specific mechanism ensuring children's transfer from maternity hospitals to public care institutions with clearly cut time frames, and to make a decision as to HIV positive children's attendance of children's institutions.*
3. *To prevent institutionalization of HIV positive children, it is necessary to develop and put into practice the system of social supervision over families with HIV positive children, including financial support, psychological counselling and additional support to HIV positive mothers.*
4. *In order to ensure the child's right to be raised in family environment, supplementary administrative and organizational activities should be conducted and regulatory documents should be completed pertaining to HIV positive children placement into foster family care.*
5. *Standards for HIV positive children care, maintenance and treatment should be developed and implemented.*
6. *Monitoring and control system over HIV positive children status and exercising of their rights should be designed and put into practice.*