

## **«Support for HIV-positive children. Experience of Caritas Ukraine»**

**Dzvinka Chajkivska, ICF “Caritas Ukraine”. National coordinator of Health program.**

According to the experts' estimates, situation in Ukraine depends to the most complicated in Eastern Europe. Our country falls into distressing list of leaders among Europeans countries in the spread of human immune virus (HIV).

Daily 50 new cases of HIV infecting are officially registered in Ukraine, but factually the number is few times higher. According to the experts of UNAIDS and WHO nearly 1,63 % of adult population of working and reproductive age live with HIV, among them 80 % of infected Ukrainians are from 20 to 40 years old. Number of AIDS-related deaths and children-orphans lost parents increases constantly for the last years because of epidemic. For 10 years the state program of preventing mother-to-child transmission during birth has cut the share of such transmission from 28% to 6%. At the same time the number of HIV infected pregnant women increases in Ukraine. It is estimated for the last 10 years from 2000 to 2010 their number had risen from 1843 to 6514 people. Number of children born by HIV-positive mothers increased 6 times.

Last tendency in Ukraine shows that part of HIV transmission through injection drug use in general number of HIV- positive people slowly decrease giving place to sexually transmitted infection. So, there is every reason to consider HIV epidemic not as only medical, but also as deep social and working problems with serious social and economic effects for our country.

Families with HIV positive children mainly have low material income and one or both parents are drug addicted. Children usually are raised by the only mother or old relatives (grandma and grandpa, or great-grandma, and etc). Half of these families have poor living condition or have no their own homes at all.

According to the active Ukrainian legislation free medicine and vitamins, and formula and baby nutrition and material aid are guaranteed to all HIV-positive children. However, AIDS centers, supplying such assistance, have no sufficient number of social workers to accompany families with HIV-positive children. Also, unfortunately, from the other side, high level of stigmatization doesn't let each child to feel safe in kindergartens, schools and children groups.

Taking into consideration the situation, ICF “Caritas Ukraine” directs its activities into medical and social accompaniment of HIV-positive adults and children with the aim to stabilize family situation and assist them to keep a child with family as long as possible (to avoid institutionalisation).

Charitable Institution “A.Sheptytsky Hospital”, founded by the UGCC, mutually with All-Ukrainian network of people living with HIV/AIDS and Regional Center of AIDS prevention implements project “From heart to heart” since 2003. According to the project we hold medical and social accompaniment of children suffered from HIV/AIDS.

Target group: children aged 2-16 years old who take ARV therapy and these who are prepared to medicine prescription; their parents/guardians; and children of socially unprotected families.

Integrating together HIV-positive children and other children without status helps to feel equal and to overcome communicative barriers of children and parents, and form model of staff behavior.

MDC works on the base of the Hospital. It includes a teacher, a social worker, a psychologist, and a pediatrician (from AIDS center).

Supplied services:

- Pediatrician consultation;
- Teacher consultation for children and family;
- Psychologist consultation;
- Consultation of social worker and organization of supplying social services;
- Assistance in taking CD4 and viral load;
- Monitoring tolerance to ARV;
- Control of taking medicine;
- Care at home or hospital;
- Humanitarian aid (foodstuff and hygienic supply, medicine)
- Holding lessons on children creativity development;
- Holding cultural measures (visiting Lviv puppet theater, circus performances, visiting museums)
- Feasts celebrations “St.Nicolas Day”, “Day of children protection”;

Hospital staff controls implementation of parents (guardians) duties: supporting personal child hygiene and nutrition, regular medical observation, holding preventive measures.

One of important direction of our work is to open status for a child. Parents usually do not inform child about her/ his HIV status because they think that:

- Their child can't understand because of age (66%)
- They do not know how to explain (11%)
- Afraid to make child psychological trauma (6%)
- Doctor or another specialist will explain to their child (3%).

That's why all members of MDC got special trainings and education to work with children and their parents/ guardians in case to acquaint them with status. Proper programs are worked out for each age group.

Supplying medical and social assistance outside of specialized AIDS centers solves many psychological and social problems and forms tolerance to children and adults treatment.

I would like to share a story from our experience. Within the project “From heart to heart” we assisted family having both parents drug addicted and with AIDS. They brought up the HIV- positive boy who had taken ARV at that time.

Mutually with doctors of AIDS center who provided medical therapy of parents and child Caritas staff carried out social and psychological accompaniment of family. We assisted with foodstuff helping to set

positive atmosphere in family and prepare the child to open his status. We helped mother to resume relations with her family.

Grandma from a village took care of the boy after parents died. Starting to live with grandma at her home the boy life had absolutely changed. With the loss of his parents he lost friends and got worst living conditions at the same time (there are not hot water and sanitary conditions in the village).

Psychologically grandma was in crisis too. After her daughter loss she didn't know how to communicate with a teenaged boy (he was 9 years old) who was incurable with "scary" disease. She had to come to the city AIDS center to take medicine for the boy and to get periodical doctors' consultations. She was afraid to be seen by inhabitants of her village and to open their secret of boy illness. So, she couldn't bare it. The boy stopped taking treatment. Hospital staff and staff of AIDS center made mutual decision to hold treatment and boys consultations at the Sheptytsky Hospital. Social worker was getting medicine, nurse was taking blood for controlling tests and pediatrician of AIDS center was setting systematic consultations at the Hospital. The grandma and the boy started to participate in measures held for children of the project. So, again he was able to be with friends and receive proper psychological support. Staff paid lot efforts to prepare grandma and boy to open his status.

Not every story has its good end. It is important to work ensuring better life even for a one child.

Experience of Caritas Ukraine activities on HIV/AIDS shows importance of giving chance to a child to live in dignity and have better prospects for the future.