

Limitations and restraints for providing services for children and adolescents

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General information

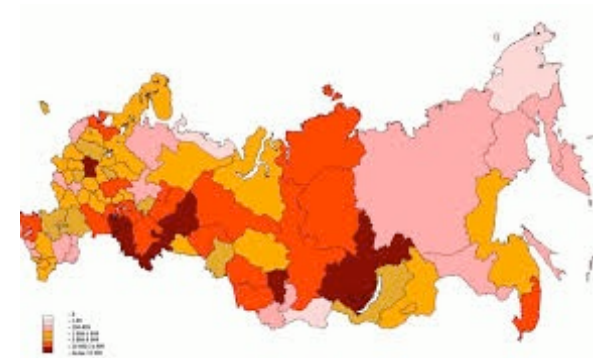
Russia:

Population – 146,544,710 people

Territory – 17,125,191 km²

Number of regions – 85

Capital – Moscow



Sverdlovsk Region:

Population – 4,394,600 (3% of Russian population)

Territory – 194,300 square kilometres

Administrative center – Yekaterinburg



HIV/AIDS data

Russia:

- more than **1,000,000** cases of HIV infection are registered
- estimated number of HIV positive people is **1,500,00 - 2,000,000**
- **50,000** people died of AIDS
- **8,000** children were infected at the birth

Sverdlovsk Region:

- about **86,000** cases of HIV infection are registered (8% of all Russian HIV cases)
- prevalence – 1983/100 000 (1,98%)
- more than **6,700** people died of AIDS
- there are more than 1000 children, **890** of them were infected at the birth
(11% of all Russian child cases)

What do HIV positive children and adolescents need?

1. Qualitative medical care.
2. Normal living conditions, provision of primary needs, and opportunities for harmonious development.
3. Physiological, psychological and emotional well-being.

Limitations and restraints for providing qualitative medical care

Limitations	Restraints
1.1. Inaccessibility of specialized medical institutions.	- In many regions state AIDS centers are situated inconveniently; travel fare is high; transport system is awkward; there are huge traffic jams in big cities.
1.2. Insufficient participation of social services in organizing of a child treatment.	- Legal base identifying the level of Well-being of an HIV positive child in a family, health risk assessment and order of transferring responsibility for the child's treatment is imperfect. - Resources of social support services in solving social problems of families are limited.

Limitations and restraints for providing qualitative medical care

Limitations	Restraints
<p>1.3. Noncompliance with rules of medical follow-up and treatment of HIV positive child by parents.</p>	<ul style="list-style-type: none">- Parents are unable to organize treatment of child because of the peculiarities of their life style. There are not enough support services for parents who aim to give up using drugs or learn to control their life with drugs.- Parents refuse medical examination and treatment of their children for various reasons. The state institutions practically have no leverage over these parents.

Limitations and restraints for providing qualitative medical care

Limitations	Restraints
<p>1.4. Noncompliance with the rules of the antiretroviral therapy by adolescents.</p>	<ul style="list-style-type: none">- The diagnosis disclosure programs are imperfect, they don't let an adolescent opportunity to understand his illness and recognize the importance of treatment.- There are no enough professionals who are experienced in adherence issues in connection with peculiarities of adolescence period.

Limitations and restraints for providing qualitative medical care

Limitations	Restraints
<p>1.5. Limited capacities on transferring responsibility over treating a child to close relatives.</p>	<ul style="list-style-type: none">- There are no other relatives – they died or are imprisoned. - Relatives do not take part in treating a child because they do not know about HIV infection of him and his parents. - Relatives condemn the life style of child’s parents and step back from taking part in their life including the child’s life. - There are no enough services, which help families to take care of HIV positive children.

Limitations and restraints for providing normal living conditions and harmonious development

Limitations	Restraints
<p>2.1. Gaps in organizing social support to children.</p>	<ul style="list-style-type: none">- In Russian society there is no formed culture of child protection. - Technologies of receiving information about HIV positive child's family adversity by social services are imperfect. - Children themselves are badly informed about social services and have no skills of self-referral for help.

Limitations and restraints for providing normal living conditions and harmonious development

Limitations	Restraints
<p>2.2. Poverty of families where HIV positive children live, malnutrition and bad living conditions.</p>	<ul style="list-style-type: none">- Children's disability allowance is used not for child needs, but for maintenance of unemployed parents and other members of the family, for purchasing alcohol and drugs.- There are no ways to regulate spending the child benefit to provide for the needs of a HIV positive child.

Limitations and restraints for providing normal living conditions and harmonious development

Limitations	Restraints
2.3. Emotional and physical abuse in a family.	<ul style="list-style-type: none">- Children take bad attitude of parents for granted; do not know, how and where they can apply for help.- There are very few services of emergency support to children; there are practically no social services working round the clock.

Limitations and restraints for providing normal living conditions and harmonious development

Limitations	Restraints
<p>2.4. Premature aging, wrong guides and values, lack of skills for creating successful life.</p>	<ul style="list-style-type: none">- Family's "moral norms" – alcohol and drug abuse, promiscuous sexual behavior, obscene language, affrays, criminal activity – are becoming a child's role model.- There are practically no prevention programs for children from socially vulnerable families aimed at forming alternative life conceptions.

Limitations and restraints for providing normal living conditions and harmonious development

Limitations	Restraints
<p>2.5. Social exclusion, violation of harmonious development.</p>	<ul style="list-style-type: none">- In socially vulnerable families children usually do not attend child pre-school institutions, nobody deals with child development at home.- Family culture does not suppose development of children – neither children nor adults are interested in that.

Limitations and restraints for providing physiological, psychological and emotional well-being

Limitations	Restraints
<p>3.1. Emotional isolation and loneliness in a family.</p>	<ul style="list-style-type: none">- Parents do not want to discuss with children unpleasant topics, including HIV infection, because of self-stigmatization.- Parents are engaged in their own problems, they are emotionally detached from their children.- limited number of providers supports caregivers of HIV-positive children.

Limitations and restraints for providing physiological, psychological and emotional wellbeing

Limitations	Restraints
<p>3.2. Internal stigma, feeling of inferiority and otherness, psychological isolation due to the need to keep the diagnosis in secret from the peers.</p>	<ul style="list-style-type: none">- Very few services meet psychological needs of HIV positive children.- Only few organizations provide opportunities for adolescents to meet and discuss different aspects of HIV infection openly.

Limitations and restraints for providing physiological, psychological and emotional wellbeing

Limitations	Restraints
3.3. Absence of support when child is grieving after death of relatives.	<ul style="list-style-type: none">- Children may not say and adults do not understand that they need support.- Children do not know where and how to apply for help.
3.4. Inaccessibility of physical rehabilitation and sanatorium-resort therapy.	<ul style="list-style-type: none">- Sanatorium-resort therapy for HIV positive children is not funded by compulsory medical insurance.- Available financing of families is insufficient for physical rehabilitation of children.

Thank you for attention!