Building bridges to improve HIV-positive women's access to breast-milk substitutes: research from six different regions in the Russian Federation

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Russian recommendations on PMTCT state that HIV-positive mothers should not breastfeed. The Action Strategy for Children's Interests includes a point about the government's obligation to provide breast-milk substitutes (BMS) for HIV-positive mothers. Supply of BMS is based on regional budgets. Given high levels of poverty among families with children, incomplete HIV treatment coverage, and frequent interruption in ART after giving birth, there is a risk for ineffective PMTCT. We aimed to determine the accessibility of BMS in Russia and to identify gaps in the provision of BMS.

Research was conducted in six locations:

Locations:	HIV Prevalence Ranking of among Regions in Russia	The number of HIV-positive individuals in the region as of January 1, 2018/cumulative number of cases			Number of births among HIV-positive womenK during 2015-2017
		All people	Women	Children	
Sverdlovskaya	1	70 316	36 584 (52%)	919	1388 (Dataonly for 2017)
Orenburgskaya	5	22 348	10 258 (46%)	403	1 898
Leningradskaya	7	20 600	8 406 (41%)	213	557 (Data only for 2016-17)
Tyumenskaya	9	21 673	8 487 (39%)	138	1 292
St. Petersburg	12	43 034	17 343 (40%)	423	1 859
Ulyanovskaya	13	11 502	4 485 (39%)	155	687

Since October 2017, regional activists

- studied epidemiological data,
- studied regulatory documents on assurance of BMS,
- submitted requests for information to government officials,
- conducted 20 interviews with specialists at AIDS Centers and clinics,
- surveyed 89 HIV-positive mothers,
- exchanged information and experience with one another.

[1]Reference.HIV infection in the Russian Federation as of November 1, 2017.Central Research Institute of Epidemiology Rospotrebnadzor.http://aids-centr.perm.ru/images/4/hiv_in_russia/hiv_in_rf_31.12.2017.pdf

Regional advocates have proven to be successful in collecting the data. This project resulted in several bridges being built between women affected by HIV and healthcare professionals. Joint efforts were made to improve availability of BMS as part of HIV-prevention by fixing the identified gaps in the system.

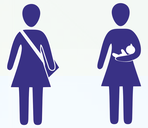
Photo of activist-researchers

This project serves as model for conducting similar research in other regions in Russia and should expanded to include other issues related to protecting the rights of women living with HIV.

Regulation of BMS provision varies regionally: same times available to all women unable to produce milk, or offered to low-income women, or based on HIV-positive serostatus and/or other medical reasons. However, it is not always available everywhere.

The survey showed that

- Only 44% of HIV-positive women were told during pregnancy about their eligibility to receive BMS;
- A set of documents is required in order to received BMS, where available;
- Two-thirds of women received formula;
- Only 25% received a full supply;
- 10% received BMS only once;
- 55% of the women needed to change formulas because they were not suitable for their infants;
- Only 14.5% received a different formula;
- Social assistance to women is associated with formal income, not only for medical reasons.



There were a lot of documents and a certificate of income, and a certificate from the place of residence, and from the pediatrician, copies of my documents and children's documents-they were all handed over to the social protection authorities.

Some providers reported stockouts in the purchasing of BMS, insufficient quantity, and the inability to provide another formula if one is unsuitable for the child. Some providers used BMS as a motivation to visit the AIDS center more often.

Young mothers noted that they do not see diversity or the choice of mixture. With allergy or intolerance, it is impossible to make a replacement, and they themselves buy BMS. Sometimes this amount becomes very large for the family - about $ 100 per month.

Activists analyzed the situation and came to the conclusion that the optimal solution to the situation may be the provision of BMS to HIV-positive women with a child under 6 months at the AIDS center using federal and regional budgets for HIV prevention for this purpose.

I applied for social protection by providing the necessary documents, but they refused me. I divorced, I have three children, and my monthly income is 34,000 rubles, they said that I do not need compensation and child support.

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