

Flying Overseas to Find a Decent Leg

By [Alexander Bratersky](#)

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Six-year-old bespectacled Sveta was excited about seeing Disneyland on her first trip to the United States.

Only the trip was not a vacation.

Sveta, an adopted orphan, started her U.S. trip with a flight to Dallas earlier this month to get a new left artificial leg attached surgically to the spot where she was born without a limb.

Before the operation, Sveta had a prosthesis purchased by the Russian government. But it was of inferior quality, a problem that charity workers say is common and the result of federal spending cuts and bureaucracy.

The Health and Social Development Ministry has allotted 12.3 billion rubles (\$437 million) for prostheses, wheelchairs, crutches and other equipment for the disabled this year, a reduction of 1.5 percent from 2010.

But securing the equipment is the bigger headache, with the application process mired in red tape. Equipment with “extra functions” — implying, among other things, quality materials — is unavailable because it creates an extra burden on the budget, according to ministry officials.

This has prompted independent charities to step in, including the program that sent Sveta to the United States.

But they can only serve precious few children — Svetlana is the sixth participant in the I Want to Walk project. Equally troubling is the fact that those who receive assistance abroad cannot get follow-up help back at home for the foreign-made equipment. Russia has an estimated 14 million disabled children and adults.

Little Sveta is one of the lucky ones. She immediately won hearts when her adopted mother, also named Svetlana, took her to an event organized by I Want to Walk, co-launched by Happy Families International and the Moscow-based Artist foundation in 2009.

“When we went to a charity event for disabled children, she simply took off her prosthesis to show her problem,” her mother said in an interview in the family’s Moscow apartment on the eve of the flight to Dallas. “American doctors organized a meeting right away.”

The driving force behind the I Want to Walk program is psychologist Natalya Shaginyan-Needham, the founder of both charities behind the program. She said she aimed to primarily assist orphans, who usually have no one but the state to rely on.

Potential adoptive parents are painfully aware of the problems they will face on their own if they adopt a disabled child, said Darya Zolotova, a member of the Detskiye Domiky (Children’s Houses) charity. “You know you cannot count on anyone’s help if you adopt such a child,” said Zolotova, whose group also raises money for prostheses for the young.

At the same time, orphanage directors are often ill-informed about where to apply for equipment and, even more important, how to tackle the bureaucratic procedures needed to obtain it, Zolotova said.

Russia does have the means to fit prostheses on children, but the system is mired in regulatory and infrastructure problems. One problem is that a free-of-charge prosthesis can be obtained only in the region where the child lives, which makes getting treatment in another region complicated.

The disabled are only reimbursed for equipment they purchase if it is on a government-approved list, said Grigory Lekaryov, a department head with the Health and Social Development Ministry.

Moreover, equipment such as wheelchairs and prostheses have to be acquired through open tenders, where the contract goes to the cheapest bid, often at the cost of quality, according to new rules pushed through by the ministry in February.

The tender rule is aimed at curbing corruption because disabled people have purchased unnecessarily high-priced equipment at the state’s expense in the past, the ministry said in January. It cited cases where the visually impaired, entitled to television sets with teletext,

bought plasma TVs and asked the government to foot the bill. But it provided no estimates of how much the state has lost this way.

In any case, law-abiding citizens have been hurt by the new rules. “With wheelchairs, the state will buy the cheapest products, caring little about their quality,” said Oleg Smolin, a State Duma deputy with the Communist Party and first vice president of the Russian Paralympics Committee.

His statement was echoed by some prosthesis makers. “The needs of a patient are not taken into the account. Tenders are won by those with the cheapest offers, not the highest-quality ones,” said a marketing executive at the Moscow office of a European prosthesis producer. He asked not to be identified to avoid backlash against his firm from the authorities.

Another issue is that most Russian prosthesis and orthopedic clinics operate separately, so a person has to get an artificial limb at one place and undergo adaptation therapy at another. There is no such problem with the Texas Scottish Rite Hospital for Children, which handles both tasks and is helping Sveta learn to walk with her new leg this month.

Smolin said independent charities are forced to send the people they assist to the West. “Others will suffer here,” he said.

Disabled Russian children should get treatment at home for practical, not patriotic, reasons, said Igor Shvedovchenko, who heads a St. Petersburg-based Albrecht medical center.

Making a new prosthesis for a child is only the beginning, because the equipment needs to be replaced every year as the child grows, said Shvedovchenko, whose St. Petersburg Scientific and Practical Center for Medical and Social Expertise is among the few in the country to handle both prosthesis and orthopedic treatment.

Indeed, while Sveta successfully obtained a prosthesis in Dallas, it remains unclear whether she will be able to return for an update. No previous participants of the program have grown enough since getting a U.S. prosthesis to require a new one.

Shaginyan-Needham said Svetlana’s prosthesis could be adjusted locally by Russian doctors. The charity is sending two doctors to the United States this summer for training.

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