

Armenia: Debate Swirls Over How to Care for Disabled Babies

March 2, 2015 - 2:30pm, by [Gayane Abrahamyan](#)
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March 2, 2015 - 1:27pm

Leo Forrest is just over a month old, but already has become a potent symbol of the struggles and discrimination that disabled children endure in Armenia. Whether his story can catalyze changes in public attitudes, however, remains unclear.

Baby Leo was diagnosed at birth with Down syndrome. As the US television network ABC reported earlier this month, doctors urged Leo's Armenian mother, Ruzanna Badalian, to give him to an orphanage. She agreed. His father did not.

"The issue lies in the society, where parents have dogmatic ideas of their children-to-be," Leo's father, New Zealander Samuel Forrest commented in an interview with EurasiaNet.org in the Armenian capital, Yerevan. "They imagine the perfect child, and when the newborn does not match that mental image, they might abandon" the baby.

Data from the Ministry of Healthcare and the Ministry of Labor and Social Affairs indicates that about 45 children are born with Down syndrome in Armenia each year; 22 of these children were given to orphanages in 2014. "Families often tend to hide their disabled children, keep them locked in, and the main reason is indirect public pressure," said Harutyun Balasarian, director of Armenia's oldest state-run orphanage for disabled children, located in the village of Nor Kharberd, 30 kilometers south of Yerevan.

One 2012 UNICEF survey of 6,042 disabled children, parents and social workers reported that many of these children may never leave their homes; still more may never leave the facilities that house them.

Lena Hayrapetian, head of the Labor and Social Affairs Ministry's Department of Family and Children, believes that while public attitudes toward the disabled are a significant factor in discrimination, the real problem lies with Armenia's lack of infrastructure for the disabled. "In our country, it is rather challenging to raise a child with special needs, which require additional care, expenses," noted Hayrapetian. Annual per capita income in Armenia amounts to just \$6,300 a year. To assist with expenses, the government gives families with a disabled child monthly assistance of 23,000-30,000 drams (about \$50-\$70). "There are few daycare centers, no community centers."

In this child-centric culture, parents do not "give up right away." Not all of the 86 disabled children who were committed to orphanages in 2014 were infants, she added. The government claims that only 13 percent of the 8,000 Armenian children registered with disabilities live in orphanages.

Some Armenian advocates for disabled children's rights contend that medical professionals are a big part of the dilemma. "When you return home with the child after giving birth, a pediatrician from a [state-run] polyclinic comes to visit, and asks, 'aren't you giving it away to an orphanage?'" said Varduhi Aramian, the director of a non-governmental advocacy group called Armenian Camp. Aramian's own 17-year-old son suffers from a musculoskeletal disorder.

"Pity is offered, rather than support or encouragement," she said of doctors, relatives and neighbors. "At every step, you are expected to either give up your child, or it will die."

Leo's father, who has filed for divorce from his wife since their son's January 21 birth, told a similar story. "The doctor told us we had the choice of rejecting him," said Forrest, who does not speak Armenian. In an open letter published earlier this month, Leo's mother described the choice as "the hardest decision of my life to be made within a matter of a few hours."

The Margaryan Medical Center, which handled the delivery, denied a request to interview the physician responsible for Leo's care.

Other doctors say that in such situations they simply explain to parents the problems that the child will face. Frustrated by the controversy, a senior healthcare ministry official conceded that "doctors should have explained the issue, informed [the parents] about the consequences, but should have left the parents to make an independent decision."

"I doubt they were given time to think it over," said Karine Saribekian, head of the ministry's Maternity and Childcare Department.

Arshak Jerjerian, the deputy director of the Republican Institute of Reproductive Health, Perinatology and Gynecology, emphasized that "the decision is always made by parents; never by doctors."

"The issue is that parents making that decision are always trying to find other reasons to justify their decision," said Jerjerian, who claimed to know Leo's medical personnel well. He characterized them as impeccable professionals.

It is "the medical personnel's attitude that misguides parents into abandoning their children with birth defects," contended Balasarian, who has worked with special-needs children for 20 years.

Disabled Armenian children raised by their families experience plenty of hardship. The 2012 UNICEF survey found that 77 percent of the 55 parents surveyed said that their child did not receive rehabilitation therapy. Forty-eight percent of the mentally challenged and 56 percent of the hearing impaired children surveyed did not attend school at all. Twelve percent claimed they had no friends.

Meanwhile, experts claim progress has been achieved over the past decade; Armenia is starting to break with Soviet-era traditions, under which individuals with physical or mental challenges should be kept apart and out-of-view.

In 117 Armenian public schools -- roughly 8 percent of the overall total -- special-needs children now are placed in general classrooms. Despite objections from some parents and teachers, UNICEF Educational Project Manager Mary Poghosian believes the policy is having a beneficial effect. In one recent UNICEF survey, yet to be published, most respondents termed "unacceptable" the idea of committing disabled children to an orphanage, she claimed.

“Attitudes change when people can see [disabled children] next to them, in the same classroom with them,” Poghosian commented.

For now, the Armenian parents of other disabled children, like Leo, can only hope that such change will continue.

Editor's note: Gayane Abrahamyan is a freelance reporter and editor in Yerevan.

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