



Case Study: Family of a Child with Disabilities

The Situation

Sergei and Katya eagerly await the birth of their first child, but when Andrei is born, they are devastated to find out that he has Down syndrome. Not knowing about the mental or physical challenges of a child with this condition, they seek advice and direction from doctors and family.

Realistic Outcome WITHOUT Firefly

The doctors and nurses at the maternity hospital don't know anything about support services for families of children with disabilities. They say that Andrei will be uneducable and will never be able to communicate with them. Since it is difficult in Russia to find a preschool and school that will admit children with disabilities, they say Katya will have to quit her job and devote herself to his care 24/7. The doctors and nurses all strongly counsel Sergei and Katya to give Andrei over to the state to be raised in an institution for children with disabilities. They say that Andrei will be happier there and that Sergei and Katya should just forget about him and try to have a healthy child.

Sergei and Katya don't want to give up Andrei, but the pressure from the hospital employees is intense. In addition, both sets of their parents want them to give up Andrei and produce "normal" grandchildren for them. Their neighbors also express negative comments about the idea of having a "defective" child in their midst. Finally, Sergei and Katya are not wealthy and while they can afford to have Katya not work for a year or two after her maternity leave ends, they can't afford to stay in their apartment for the long term if Katya gives up her job completely. With heavy hearts they sign over their parental rights to the state, and Andrei is sent to an institution. Sergei and Katya mourn Andrei for the rest of their lives.

It turns out that Andrei has only a mild cognitive disability. All of the employees, though, assume he is an "imbecile" and refer to him as such, even in his presence. He has moderate hypotonia (low muscle tone), which is fairly common for children with Down syndrome, so he spends his entire life in a crib. Without speech therapy he only learns simple words and phrases. No one shows any interest in trying to communicate with him and he withers away in silence. He dies at age 15, with a body the size of a 6-year-old due to severe deprivation of human affection, which leads to drastic growth delays.

Realistic Outcome WITH Firefly

A few of the doctors and nurses at the maternity hospital have attended Firefly's open lectures on Down syndrome and understand the importance of having Andrei remain with his family. A system has already been put in place between the maternity hospital and a rehabilitation center that was one of Firefly's pilot sites. The maternity hospital employees contact the rehabilitation center, which sends a case worker, Sveta (a Firefly graduate) to the maternity hospital to visit with Sergei and Katya.

Sveta teaches Sergei and Katya about Down syndrome. She explains that the rehab center has a mother's group that meets several afternoons a week, and a father's support group that meets one night a month. She tells them about the Firefly-trained therapists at the center who will help Andrei develop to his full

potential. She also explains that, depending on the level of cognitive disability, some children are able to attend preschool, and that specialized schools are available in Russia for some older children with developmental delays. Finally, Sveta provides them with easy-to-understand information about Down syndrome that they can share with their family and friends to lessen the stigma attached to Andrei's disability.

Because of this support from the rehab center, Sergei and Katya decide that they will be able to raise Andrei at home. They take full advantage of all the services provided by the rehab center, and Andrei thrives. Although he has moderate hypotonia (low muscle tone), which is fairly common for children with Down syndrome, physical and occupational therapists work with him every week and teach his parents exercises to do at home every day. He is eventually able to walk without assistance. It turns out that Andrei has only mild cognitive disability, and with the help of a speech therapist, he learns to speak fairly well. Andrei's grandparents learn to love him dearly, and he develops good relationships with the neighbors in his apartment building. At age 3, Andrei has advanced enough to attend preschool and Katya returns to her job. As he grows older, he attends a specialized school for children with cognitive disabilities. After completing his schooling, Andrei is hired to work at a children's bookstore, where he shelves the books and bags the purchases. Eventually he is promoted to the position of cashier. He works for decades in this visible position at the bookstore and inspires many customers by showing that a person with Down syndrome can live a productive and meaningful life. Andrei lives with his parents until they pass away, at which point he moves in with the family of his younger sister. Andrei lives a long and happy life, eventually passing away at age 52 – a reasonable life span for people with Down syndrome.

Cost Comparison of Scenarios:

WITHOUT FIREFLY
<ul style="list-style-type: none"> • Cost to raise Andrei in an institution until his death at 15 years of age: \$255,000¹ • Cost of mental suffering endured by all family members in scenario: incalculable • Economic loss of a potentially productive member of society: incalculable
TOTAL COST: over \$255,000
WITH FIREFLY
<p>Firefly's three-year training program costs \$15,000 per person practitioner. A conservative estimate is that each practitioner will add one new child/family per week to his or her caseload. Assuming a 40-week work year and a 15-year practice², that is 600 children/families served per practitioner. Thus, the training cost for each practitioner is \$25 per child/family. Service provision is \$10/hour.</p> <ul style="list-style-type: none"> • Firefly's training of 4 practitioners: \$100 • One two-hour home visit: \$20 • Four hours of medical services to Andrei for 40 weeks: \$16,000 • Two hours of parent support groups for 40 weeks for three years: \$2,400 • One hour weekly of parent-child group class for 40 weeks for three years: \$1,200
TOTAL COST: \$22,920

Please view a real-life case similar to this scenario at <http://www.youtube.com/watch?v=IWCWvzMlp3o>

¹ Data is from personal conversation in 2010 with a baby orphanage director in Nizhny Novgorod Region. The cost is up to double this amount in Moscow (see <http://www.newsland.ru/news/detail/id/712735/>).

² Due to Russia's vacation schedule and trainees being several years into their careers when they participate in Firefly programs.