

## Nodira's Story

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Nodira, which means 'unique' in Uzbek, is one of five children in a poor family. Every morning, after reciting her prayers, Nodira feeds the hens and goats from her wheelchair. The rest of her day is spent knitting for other people and helping her mother with the household chores.

Nodira is 18-years-old and lives in the Tashkent region of Uzbekistan. She was born with spina bifida, a birth defect that occurs when the spinal column doesn't close completely during fetal development. As a result, Nodira is paralyzed from the waist down. Her life is confined to a wheelchair and her world is restricted to her house and its immediate surroundings. And yet, Nodira's dreams know no such boundaries. Her hopes for the future include attending university, riding in her father's car, and being able to walk like other children. But, for now, her dreams are extremely limited by the reality of living with a disability.

Despite the many difficulties and frustrations that plague Nodira's life she is fortunate to be living with her family. The stigma attached to children living with disabilities, combined with the lack of wheelchair access in schools and the economic difficulties faced by many Uzbek families following the collapse of the Soviet Union, have led many parents to place their children with disabilities in special institutions. Children in institutions receive less attention and affection than they would in a family and many do not receive the health care and education they need. Children who have spent their lives in an institution are seldom prepared for life outside of an institution. They often don't have the job skills or social skills needed to cope when they leave the institution.

Nodira has never been to school because it is too far from her home and it is not accessible for her wheelchair. A local teacher comes to tutor her at home and, as a result, she is reading at a sixth grade level. Still, it is unlikely that she will be able to finish her primary education, much less attend university. While missing out on an education is a great disappointment to Nodira, her greatest wish—a true friend—can still come true.

"What I want more than anything is a friend who also has a disability," she says.

"Somebody to talk to that will not feel sorry for me or make fun of me, somebody who will understand what my life is like."

1. Does Nodira have any goals that are similar to your own? What are they?
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2. Do you think young people with disabilities in the United States face challenges similar to those faced by Nodira?
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Source: 2006 *State of the World's Children* report, <http://www.unicef.org/sowc06/profiles/child7.php>.