

Who's Lucky?
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It was 1995. My friend Nancy was coming to visit me in Novosibirsk, Siberia. Yes I was in Siberia getting ready for Axis Dance Troupe to arrive from the U.S. and teach people with disabilities there not only how to dance—in and with their wheelchairs and some with their limbs stiff and difficult to control—but self defense and other things. A historic moment for all involved, even my queer friends who were in for the long haul and ready to pitch in. We are all disabled, I quipped.

I was living in an apartment in one of those Khrushchovkas—typical boxy cement 5-story buildings with the impossible four steps going up to the first floor, never once were people in wheelchairs or other walking disabilities consulted, ramps never built. The apartment was pretty bare with a few chairs in the living room, a table and two chairs in the dining area and a bed in the one bedroom. Two rooms meant a kitchen and a bedroom. The bathroom didn't even have a toilet seat, which I of course added eventually.

So Nancy arrived at the rattletrap, dusty Novosibirsk airport, the same airport I had to go and argue with and cry to customs officials to get our computers released because they were being held at customs, the same airport I came into with the first power wheelchair in Novosibirsk, pretending it was mine, which I got away with by wearing a neck brace. The same airport where I met the Axis party arriving from Berkeley California with four wheelchair riding dancers and four non-disabled dancers, including Nina, and two assistants, one of whom was Leslie, who later became my girlfriend. Big buses transported everyone to the famous Fyodorov eye clinic, where they were staying because everything was accessible.

Nancy stayed with me in the apartment and on this her one and only visit to Novosibirsk, Nancy met the love of her life, Nina, one of the dancers and they are now—today—celebrating their anniversary of twenty years being together.

It was a great moment in the history of Novosibirsk, too, when people in wheelchairs came down from several stories up in their Khrushovkas to see Axis performing out in the open, in the central square, Lenin Square, around the great statue of revolutionary Russian leaders, in front of the great Novosibirsk Opera theater, where some of my gay friends worked and sang.

It was a great moment when at the dance workshop, one of the Russian participants, who had cerebral palsy, came up to me with effort and smiled with tears streaming, saying “I never ever thought I would ever in my life do this—dance.” I hugged him. And, one of the post-polio affected women who fell in love with a wheelchair rider, who hidden in his apartment up to this very moment in Novosibirsk history, wheeled her around outside on his lap, and she, looking like Marilyn Monroe, waved her metal crutches around and declared she too would start a dance group in Novosibirsk—who wants to join?

And so much more. I remember one of the women leaders, Lyuba, pointing out the similarities between lesbians and people with disabilities in her high-pitched voice: we are both marginal, right?—people look at us on the beach as they do you, like we are strange. And also, we like using dildos and you do too, right? A big laugh. It was the same rise in inflection both times...

Many more stories, including several disabled women being queer-curious, including one who really couldn't relate to her husband anymore but took a shine to me. I was lucky, oh so lucky to have all these experiences. I was lucky to meet Leslie and Leslie me; Nancy was lucky to meet Nina; the Novosibirsk community was lucky to meet Axis and vice versa. Everything changed. And more.

Something is missed in the writing that I remember grander in the telling. I have told the story many times, for example, of how we were at the airport, after everything in Novosibirsk— all the great modeling of independence and art and self-defense. Then in the airport, these amazing people, the ones who just danced around Lenin's larger-than-life statue, wheeling wildly and arcing arms higher-than-life. These very same people were being treated as ill, as patients with a sickness, incapable of mixing with "well people" on the plane.

I could see the pain and exasperation in Judy's eyes, her sigh of protest. Years, decades, of this attitude, this ignorance. Since I was the one speaking Russian, I spoke for them—but they are not sick, I said, they just use wheelchairs, they are perfectly healthy. Officials shook their heads again and again citing rules. I remembered crying desperately to the computer police at the Novosibirsk airport, who really intended to confiscate our computers. How glad I was that I made a scene because I got them back. But now, I don't know. They wouldn't budge.

They were wheeled into the exam rooms, taken by ambulance to the plane. Our dear friends were subject to able-bodied officialdom, couldn't do anything else but go along with it, if they wanted to go home. A sad ending to a great trip.

And another thing. I also liked telling the story of Sveta, the thirteen year old girl with cerebral palsy, her head leaning to the side because she couldn't hold it up, her eyes vibrant, yet nothing much she could do. She wasn't taught anything or helped at an earlier age. Her parents' devotion masked their hopelessness about her limitations.

Somehow I connected with her. We liked each other. No way to turn this situation around, I thought. She had so much inside her, so many dreams. Her mother was so used to chewing her food for her. I brought her a doll with a

button on her foot to be pressed. "I love you," said the doll in English. Sveta pressed it over and over. It didn't take her long to learn and we "entrained." There was some kind of connection and I felt fortunate.

She wanted to go places and be with people but her parents were tired. She got an infection. I wrote a few times from the U.S. Her father wrote back once and said Sveta remembered me. But I was not there, I was not there.

Then there was silence and when I went back to Novosibirsk years later, I found out she had died.

There is no way to describe that connection, that pleasure, or why I didn't do more. Being together was what was special and will always be special for me. Extraordinary. Not something writing would help, or including it in a book. Wouldn't get anywhere. It was/is my own experience, my own feeling of love and connection. That look in her dark eyes aslant, and what she thought about as she looked at mine at an angle—I don't know.

All I have is my own experience that Ursula Le Guin calls entrainment. I didn't spell it wrong. It means being in sync, a brainwave thing, brainwaves dancing in rhythm. For that, you have to be in each other's presence, not far away in two different countries or cities, not writing stories or letters. It's not love of the highest kind, it's just a kind of love.

This is the story, the story that was excluded, the story I missed telling because the dance was not there.