

Jacob and his princesses

By MARCY WHITE, Special to cjnews.com

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“Have you lost your mind?” Megan shrieked into the phone after I told her about Jacob’s summer plans. My friend did not attempt to hide her disapproval, which was heightened when I told her three Orthodox Jewish teenagers would be responsible for his well-being.

Marcy White and her son and Jacob Trossman

Maybe I did lose it, I’m not sure. And I started doubting my parental abilities, again.

Jacob, my green-eyed son, has Pelizaeus-Merzbacher disease (PMD) a degenerative neurological disorder that prevents him from sitting by himself, walking, talking and swallowing. It does not, however, impair his ability to understand conversations or affect his amazing sense of humour.

As a parent of a child who cannot speak or move independently, is it irresponsible of me to send him to Camp Yaldei, an overnight camp, with teenage caregivers whose lifestyle and beliefs are different from mine?

The first time I noticed the figures in black was when I was a child going to the bagel factory with my parents on a Saturday night in Montreal. The bagels were hot; the car windows would fog up during our drive home and filled the interior with the aroma of warm bread and sesame seeds. I remember watching the men dressed in black suits and black hats during the hottest nights of July.

Following a short distance behind these shadowy figures were the women, wearing shirts with long sleeves and long skirts, pushing baby strollers, older children holding the hands of their younger siblings. I watched these people and wondered why they chose to have so many children, why the women agreed to wear wigs, and I thought how awful it must be for the children to be raised without television.

When Jacob was 16 months old, I hesitantly enrolled him at the Zareinu Educational Centre, a school for children with medical, physical and developmental challenges. I was reluctant to take him to the program for several reasons, one of which was that it was run by the Orthodox Jewish community. I feared Jacob would not be accepted because our family was not religious; we did not even belong to a synagogue.

At first, I was uncomfortable in that surrounding. It was difficult being in a group with eight babies and toddlers with various challenges, but it was even harder when I realized that Jacob’s issues were the most severe and complex in the class. Nobody commented when I wore jeans to class instead of the long skirts preferred by the other mothers. When Jacob was engaged with a therapist, I had time to chat with the others. I learned a lot about their religious beliefs, and I started to realize how misinformed I was.

A few years later, I saw a flyer for a weekly program for kids like Jacob, children with special needs.

Yedidus, which loosely translated from Hebrew means “friendship,” was held at Bais Yaakov High School, an Orthodox school for girls. I considered sending Jacob but was concerned that the lack of adult supervision in the program would expose my son to danger. My friends, Megan included, ardently supported my decision. They convinced me that I should not leave my defenceless little boy in the care of girls who some would consider children themselves.

The following year, when Jacob was four years old and I was desperate to find an activity for on the weekends, I enrolled him in Yedidus. The group was organized by girls dressed in long, dark skirts, their hair styled in identical ponytails. They were kids in grades 10 through 12 and ran the program every Sunday morning when most teenagers are still sleeping, tired from a night out partying with their friends.

This religious community gives their children more responsibilities at an earlier age than those who lead a secular life. They marry younger, have children younger and are taught to be charitable, financially as well as with their time, at a much younger age. A 16-year-old in the Orthodox community is much more responsible and more interested in helping a neighbour than a typical teen, who is more concerned with the hottest music and the latest trends.

Some of the most wonderful examples of compassion and love are showered on Jacob when these kids play with him, talk to him and spin him in circles to make him laugh. These girls, who dress in skirts that fall four inches below their knees, help reinforce Jacob’s younger sisters’ belief that princesses only wear skirts.

Jacob is a fixture at Bais Yaakov on Sundays and is adored by almost all the students at the school. At 10:30 on Sunday mornings, as I push his wheelchair into the driveway of the school, Jacob starts squirming. His obvious excitement when he realizes where we are is restrained only by the seatbelt and foot straps that secure his body to his chair. The chorus of high-pitched “hi, Jacobs!” erupts as soon as the first teenager spots us. As we enter the building, a counsellor affectionately whisks Jacob out of my arms and plants kisses on his soft cheeks.

Sarah, Jacob’s counsellor during his first year at Yedidus and his favourite person in the world, has seen Jacob at his best and at his worst. Just mentioning her name makes him smile. Hearing her raspy voice on the telephone is enough to stop him from screaming regardless of the cause of his upset. She has witnessed Jacob’s choking episodes, seizures, hives, general discomfort, and more than one episode of projectile vomiting. She is extremely capable with Jacob, and I often forget she is a teenager.

Some of my family and friends shake their heads in disbelief (or is it disapproval?) when they hear we have no qualms about entrusting Jacob’s well-being to this group of girls. They look surprised (or is it shocked?) that these kids know how to feed him through the tube in his stomach, an activity most adults in my life are too fearful to learn. I imagine they would consider me irresponsible (or is it crazy?) when they learn about his latest adventure, three weeks at an overnight camp in a neighbouring province.

But I won’t let their opinions sway my decision this time. I know Jacob will have an incredible experience surrounded by people who love him and enjoy making him happy. I know he will be safe. And I know that I am lucky to be part of this warm and generous community.

Marcy White lives in Toronto.