

KEVIN'S EMPOWERMENT GROUP

By Joan Gray

Our son, Kevin, was diagnosed with autism at Sick Children's Hospital in Toronto when he was four. Thirty-six years later he lives semi-independently in his own apartment with the help of a microboard.

The diagnosis of autism was devastating, but it came at a fairly early age, and we were fortunate to have Kevin enrolled in an opportunity class shortly after. The teachers were intrigued and dedicated themselves to his education. He learned to express himself through his art, then he learned to print and to type, and eventually he learned to read. He skied with his younger brother, and he swam and canoed with the family in the summer. He was included in most family outings, which included eating in restaurants and a trip to Disney. But, living with a child with autism took its toll on the family, and at age 18 when Kevin expressed a desire for more independence, he left home to live at Melanie's Place in Thomasburg, a home for adults with autism. He gained more skills, but he actually had less independence, and he began to express a desire to return to his home community. In 1989, Kevin came back to our community.

We have had a rocky ride over the years as we balanced Kevin's desire for independence with his need for help. I will never forget the first time he slept overnight in his own home. That night and for weeks after I drove by his home at 11 p.m. If the lights were still on, I drove by again at midnight and again about 1 a.m. I wasn't satisfied until the lights went out. I was introduced to many all-night doughnut shops. And my husband learned to cope with my motherly ways as I tried to let go. We also had to learn to decipher Kevin's many varied ways of communicating. After he cut the telephone cord on three separate occasions, we finally learned that he didn't want staff chatting on the phone when they were with him, and we had the phone removed from his home. Kevin has been hospitalized on a number of occasions for a possible bi-polar disorder. The last time he had thrown a variety of foods and condiments around the apartment for several weeks, he had broken plates, etc., all behaviours connected to food and to staff. The very insightful doctor asked me just prior to Kevin's discharge how I would feel about withdrawing staff. I admit I had thought about doing this on a number of occasions, but now the doctor was giving his approval, and it worked! Now Kevin prepares his own breakfast and lunch each day, and he sometimes offers and makes tea for guests.

He currently lives in his own bachelor apartment with limited staffing. Kevin had a very wise grandmother. When he was diagnosed at four years old, she invested a small amount of money in GICs. Last year, the proceeds from the investments were used as a down-payment on a house that was purchased in trust for Kevin. The house is an older style which backs onto a hill and which has a deep front yard. There is a house to one side but empty space on the side next to the apartment, so it provides the privacy that is needed. The apartment is over the double garage that is attached to the house, and there is a common room between the apartment and the main house.

I was introduced to the concept of a microboard in the fall of 2002. Two of my very dear

friends supported my endeavours in this regard, and we visited Elizabeth Bloomfield in Guelph where she has a similar but different living arrangement for her son, Andrew. Elizabeth kindly provided us with the information we needed to incorporate. The objects and template by-laws for her Board are posted on her website <http://www.ont-autism.uoguelph.ca/microboards.shtml>. She is very knowledgeable and very willing to share. We completed and submitted the application form, which was provided by our lawyer, and with minimal changes, we received our letters patent in April 2003, two months after Kevin moved into his apartment and about a year after we began to investigate the possibility of a board.

We currently have five members on our Board, which we call Kevin's Empowerment Group, or KEG. My brother is the secretary, one good friend is the treasurer, the second good friend and my sister are members, and I am the president. It is preferred that the individual be a member, but for various reasons this is not the case for Kevin at the moment. The key here is that the Board makes all decisions, which brings with it a great deal of responsibility, but also the best possible program for Kevin. To assist KEG, Community Living acts as our support mechanism.

Recently, we hired a coordinator who looks after the administration, but who is also a part of Kevin's program. She, or one of two part-time staff, drop in around lunch time to make certain morning meds have been taken, and one of them supplies a hot dinner on weekends. Another woman lives in the house rent free, heat and hydro included, in exchange for which she has contracted to be on the premises from 9 p.m. to 9 a.m. every day with alternating weekends off. She provides meds for Kevin at 9 a.m. and with dinner four days a week, and she leaves a vitamin with his popcorn at 9 p.m.

KEG's vision is that Kevin will live in the community as a valued/contributing member. Board members, staff and friends work as a team to make this happen. Kevin makes his own choices when possible and staff support him in this. We try not to be intrusive, but we all find ways to spend small periods of time with him. We encourage staff to be perceptive and to listen to what Kevin is saying. He often gives clues, and we need to let him know that his words have meaning and that we are willing to help him. We all work together to help Kevin to lead an active life in the community.

It is rather difficult to determine if Kevin is satisfied with his latest living situation, but he is becoming more and more involved in his own day-to-day living, and he is beginning to reach out to people from his past. It seems apparent that giving plenty of choice is paramount to Kevin's success, and the microboard is successfully allowing this to happen.