

The Jonathan Sweet's Story

Judith McGill

When the Sweet family began moving to create a home of one's own for their son, they learned about how a microboard could offer some needed structure. Here is Jonathan's story. The interview is with his mother Carol, father Earl, brother Andrew, family friend Xiaobo and Kelly Casey a friend and person-centred planner.

Judith

Can you speak about how you got started developing a microboard?

Earl

We started setting up a microboard about three years ago. Kelly had arranged a series of meetings for parents in our region called "Why Wait".

In other words, why wait to have your child go to a group home, perhaps there might be other alternatives? A number of families got together to explore housing alternatives. One of these meetings brought up how microboards could be used to provide relationship support for someone in the long run.

Judith

How did you go about deciding who to invite onto the microboard?

Earl

We have nine Directors, which is the maximum for a microboard.

When we were choosing who would be good to have as directors, we thought well, there's the obvious ones, which are Carol, myself, Jonathan and Andrew, Jonathan's older brother. Then we began thinking about other family members and invited our two nephews and one of their spouses, Joshua, Noah and Sarah.

Then we began thinking about our friends. Before we even decided upon a housing arrangement for Jonathan or formed the microboard, I had been discussing these issues with Xiaobo. I met Xiaobo while commuting to work and, subsequently, his and my family became friends. I began telling Xiaobo about my son and our vision of helping him to create a home of his own. He had a significant amount of experience in the fields of finance and risk management and our discussions and his feedback were instrumental in guiding our final decisions. I also had the chance to discuss the concept and use of microboards – a specific type of not-for-profit corporation – with Xiaobo while on the commuter train or over lunch and eventually asked if he'd be interested in joining the microboard, and he very readily agreed to become a director.

We've known Kelly ever since she was a girl, when we were living in Beaconsfield near Montreal, where she used to babysit for us. Many years later, when we moved to the Toronto area, we bumped into her at a "Why Wait" meeting, which she had been organizing. We asked her to join Jonathan's microboard and she has been helping us think about microboards and housing arrangements ever since.

There are some official roles within the microboard, so for instance Kelly is the Secretary, I am the Chair, our son Andrew is the Vicechair and Carol is the Treasurer. There have been some natural roles that have been brewing at the table. Xiaobo is great with accounting, planning, and risk management -- some of his natural strengths.

Recently, at one of our microboard meetings, we discussed the use of technology to perhaps permit Jonathan to be by himself at home without a caregiver for a short period of time, using cameras for safety reasons. Joshua, one of my nephews who was familiar with that group of cameras, said he would do an assessment and make a recommendation. Although, we decided not to go in that direction, it has been very helpful to have all of this talent around the table. Even though we decided we didn't want to put cameras in his place because it might make his live-in caregivers feel uncomfortable, we were able to make an informed decision.

Kelly

Sarah is really good helping with Jonathan's communication and building relationships. She has known him for a long time. Because of the relationship, she is able to inspire him to learn and try new things.

Earl

You'll notice all these people we have on the board are a lot younger than we are, which of course makes a lot of sense, given that succession in decision-making is a crucial issue. Having people, we trust gives us encouragement, peace of mind and reduces the stress of having to make a go of it alone.

Xiaobo

When Earl asked me to get involved, I figured I am a little younger, if I can help I will. At the time, I did not know how the microboard works but I thought at least as a friend I can help. When I heard Kelly describe how a microboard works, I thought it would be good for Earl and Carol. Rather than doing it all by themselves or relying on siblings or other family members, this would help them to get others involved.

Kelly

The reason I said yes to joining Jonathan's microboard, is that I work in this field because of my love for what I do and my love for connecting with people. I love working with families, but it becomes a different connection when you've known people for so long. I knew Andrew, Jonathan's brother, since he was two years old. It's a real connection versus a professional connection. It means so much more to me to be a member of the microboard. It's more like extended family versus work for me. If I have a gift and I am finally able to share that gift with somebody, why not it be a family that matters to me?

Judith

What have been the greatest benefits to Jonathan and your family?

Carol:

I think that once Kelly helped us find a vision for Jonathan and set some goals it made a big difference. Everybody on the microboard has had such a positive effect on Jonathan. They understand that he is a gift -- he is not a burden in any way. He has gifts not deficits. He has opportunities not obstacles. He is now growing from being part of that kind of an atmosphere, with new opportunities.

The benefit to Jonathan has been amazing. Since Jonathan moved out into his own house, he has had a new sense of independence. He is so proud he is living in his own house with his new friends (live-in caregivers). He is just getting such positive role modelling from them. Leaving his mom and dad, just as his older brother had earlier, made him feel so good. We can tell now that he was ready for this. He has begun talking more. He is making more choices. He is just coming into his own like we've never seen before. We are just so forever grateful for that.

He has gained confidence. I think that started when he had other people in his life. He slowly began enjoying being out with other people. When he returned home, he would ask when he is going back out again. He wasn't upset about us going places without him or upset when we came back.

Andrew:

As Jonathan's brother, I really appreciate having a microboard in place. It's a great support to have people who know and care about Jonathan available to help with decision making, so I'm not alone in this responsibility.

Judith

How do you support Jonathan to make decisions?

Xiaobo

We started with Carol and Earl's vision. We believe that as Jonathan becomes more mature and gets used to having a home of his own, he will have more of a say about his life. Already he is maturing and has been given the opportunity to step outside of his comfort zone with help from his Support Workers, family members and microboard. I see him become more independent over time which would be a definite blessing.

Earl

One of the things that I have found since Jonathan moved into his own home with his live-in caregivers is that Jonathan is more assertive. He lets us know when he doesn't want to do something with us. Sometimes he really is happy to go for a walk with us but there are times, he just says "No I don't want to."

He used to show his stress and anticipation outwardly, showing it vocally or physically, but we have seen much less of that than in the past, which is a real positive. Since he has had a home of his own, he talks more about the here and now versus talking about the past. He now chooses to talk about the future more. We can talk now talk with him about what is happening and what are the sort of things he would like to do. He is also expressing his opinions much more assertively than he has in the past.

He is more independent when he is with us. When we go for walks together, he likes to walk ahead of us. On arriving at cross-streets, he used to wait until we caught up to him and wouldn't cross the street without us. We have spent a lot of time teaching him how to cross streets safely and now he will sometimes cross before we catch up with him, which is great for his independence. He is really careful, and we've noticed that now, after many discussions about the coronavirus virus pandemic that he keeps himself safe.

We are thinking of making a book about Jonathan, what he likes, what he doesn't like to do, and which foods should be avoided, so that other people can come to know him like we do. Jonathan could help make the book and show others what he is doing. Though Jonathan doesn't like people talking about him we are trying to find a way to engage him as much as possible.

Carol

We also noticed an improvement in Jonathan's self-confidence while walking with him and coming across a barking dog. . Previously, he was always so anxious on walks because he was always anticipating that a dog might bark. He wasn't particularly fearful of dogs; he just didn't like the uncertainty of whether there would be barking. Now he walks with more confidence and just walks right past dogs on the street. He doesn't turn around and plug his ears anymore.

We feel really fortunate with Jonathan's live-in caregiver and her husband who are warm and caring individuals, who take him out a lot into the community. Jonathan is enjoying his life and, prior to the pandemic, he went out on a daily basis, either to art or music class, trampoline, for walks, and volunteering at the local mission store. We see how welcome he is in the community and how people show a lot of warmth to him. Johnathan has other caregivers that take him out into the community when his live-in caregiver is off duty and Jonathan frequently spends his weekends with us.

Judith

What have you done so far in regard to succession planning?

Earl

One of the essential aspects of a microboard is of course that the directors, or at least most of the directors, be a lot younger than the parents. This makes it possible for the microboard to continue to function effectively after the parents pass on. It is also essential that there be procedures in place for the succession of board members, to ensure that the microboard works effectively over

Jonathan's lifetime. It is possible that some of the children of existing board members may wish to become directors at some point down the road.

Xiaobo

When I put myself in Earl and Carol's shoes, knowing that Jonathan is a very healthy young man, I think he could live another 40-50 years and so we need to plan for the long run. He may even outlive me, so I feel that the board needs a strong succession plan. I am already planning for the next generation. I have one daughter and three sons, and I try to bring my three sons into the picture so that we begin really thinking ahead.

It is really helpful that the microboard has different members who can provide different perspectives. It is a good sounding board for Earl and Carol. Especially because some decisions have been harder for them to make alone.

I work in the corporate world, so I have had to deal with boards directly in my work. Right now, I am working for a family office, so I deal directly with the family. I can see that all things good and bad, can happen in a family, so it's good to have a formal way to make decisions. It is good to have a board and not just a single person making decisions. A board has clear rules and responsibilities, and this brings order. It's not an easy task to figure things out for Jonathan, it really requires a lot of coordination.

At this point, Earl and Carol do a lot of the coordination. That's why we say our microboard is still working on succession because we still need to move to a stage where they can take a back seat and don't have to do all the heavy lifting.

Carol and Earl are still healthy so I figure that may still have twenty or thirty years to go. This will let us learn step by step. On the other hand, I feel we are going to need clearer roles and responsibilities for the members. We need a succession plan so the parents can really sleep well during the night and not have to worry too much about the future.

Judith

What challenges have you faced as a microboard?

Earl

We haven't always known what comes next and it was a little bit intimidating at first. One of the things that helped was of having Kelly's support because she was more familiar with the process than we were. The seminars we went to with other professionals, such as lawyers who specialize in microboards and housing alternatives were very useful.

Something we definitely feel we still have to improve at is having regular board meetings. It's just something we really need to do. Many of the people on the board have very young families and so they are busy with their families and it can be tough to get everybody together at the same time.

We want to make sure that if we are having a board meeting, there is something really important to discuss and make a decision about. We also want to find ways to strengthen the Board members relationship with Jonathan and ourselves. We hope to build the social aspect more with informal get-togethers over the next year.

Xiaobo

I have noticed that as parents sometimes they worry too much about burdening the microboard members and that makes it even harder to reach out. It is helpful to have a schedule of meetings in advance, so everyone can know to put that time aside. If some people, one or two members cannot attend, that's okay. Even for a corporate board, not everyone can participate at all times. The reason we joined the microboard is because we really want to help.

I can understand, you guys feel healthy, and you have lots of time on your hands. We do have to plan ahead when times are good. If we formalize when we meet, we can form a kind of habit and it will become a routine. We can even start using Zoom videoconferencing for meetings. We definitely should leverage technology like google docs. It's good for our succession planning and it can be a living document.

Kelly

There are lots of ways for the microboard to meet. Nothing has to be done at a board room table. Discussions and decisions can be made over coffee or even while going for a long walk. They could be made anywhere. It's just about documenting it after if there is something significant.

Earl

One of the big challenges that we anticipate is when the live in-caregivers tell us it's time for them to move on and we need to find someone to replace them. It's going to be very difficult and we will look to the microboard to help us think that through. It is a real worry because it's very difficult to find people who want to offer live-in caregiving now.

Judith

What have you learned that you would want other families to know?

Earl

We would recommend to families that are much younger than us to start as soon as possible. Just get the conversation going, just talk to others who have chosen specific types of housing models so that they can understand the pros and cons and see what might work best for them. After narrowing down the options, then go and find out as much as you can about the legal and financial aspects. Having a friend like Kelly who is a professional in the field and a lawyer like Brendon Pooran, meant that it wasn't so overwhelming.

Carol

I guess what I have learned, is that I am reluctant to ask people for help because I don't want to burden people. For people to just offer this help, and be so loving and gracious and caring, is so heartwarming and encouraging. I have learned how to ask for help because of this process. The microboard members have made me a better mom and helped me learn how to let go and let Jonathan be the best he can be. It has made such a difference. The whole process made it so much easier than we could have possibly anticipated. The thrill for me is to see Jonathan growing and developing and being happy. I've never seen him so happy! That makes it all worthwhile.

Kelly

I learned about the importance of relationships. Having the ability to have a role and grow a deeper relationship was a surprise to me. I heard people talk about, "if you have a specific role in life, relationships will blossom". But for me philosophically talking about it and then actually doing it was different, now I believe it. Actually, knowing what my role is in your life, and Jonathan's life, has made it easier for me to continue being open to spending time with all of you. It really matters knowing where I fit in supporting your family.

Carol

I would like to give special thanks to the Microboard Directors for the tremendous support they have provided in helping us set up the microboard. Kelly's personal and professional support provided us with the encouragement and impetus to start the at times difficult but ultimately highly rewarding journey with Jonathan. Her focus on looking forward and taking steps in a systematic way and her in-depth knowledge of the use of microboards helped us to overcome any inertia that we initially had, for which we are extremely grateful.

Earl

Having an estate plan with a proper Henson trust that ensures that the individual is not disqualified from receiving provincial support such as ODSP is crucial. The trustees of the estate are different from the people that are directors of the microboard, although some of them might be the same. In terms of managing risk, it may also be advisable to hire support staff through the microboard, which is a corporation has limited liability. To limit financial risk to directors, it is important that the microboard arranges for the proper insurance -- general insurance and directors' insurance. Of course, all of these issues should be discussed with the appropriate professionals.

When we first started helping Jonathan create a home of his own, we decided to sell our home and purchase a larger property north of us, where of course the land prices are less expensive. We bought a property that had a house on it, but it also had a very large garage workshop at the back of the property that we thought we could turn into a residence for Carol and myself. We thought that Jonathan could live in the main house with a couple that would offer live-in caregiving. We needed to receive permission from the city to turn the garage workshop, which was kind of broken down, into a place where we could live.

That, plus the process of arranging for the necessary building permits, took quite a long time, but we finally got to the go-ahead and turned that garage workshop into a residence where Carol and I are now living. In the interim, we were living in an Airbnb and friend's houses for about seven months until our contractor finished the work. We now live only about 100 feet or so away from Jonathan's house, though that 100 feet provides a sense of independence to both Jonathan and ourselves.

After two years, Jonathan is now very happy to have us here and he comes to visit us on weekends. He comes to us on Friday evenings and has dinner and sleeps over and stays with us on Saturday and Sunday and then goes back to what he calls "his house" on Sunday evening.

We went through about two and half years of stress dealing with various issues and at the same time trying to set up the microboard. My key message to families is, do not leave it too late to do this. Do this while you still have a lot of strength and energy. Don't leave it to the last minute because it can be time consuming and it requires a lot of energy, stamina, and perseverance. While there certainly, have been lots of bumps in the road, we feel that we are definitely moving in the right direction and we are really glad we still had the energy to make this work