

The Jonathan Lim Story

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Three years ago, Jonathan's family gathered to learn all they could about how to set up a microboard so that they could help him to plan for his future. Here is Jonathan's story. The interview is with his mother Imelda, father Ray, his sisters Victoria and Andrea, his brother-in-law Alvin and Kelly Casey, his person-centred planner.

How did you come to know about microboards?

Andrea

I heard about it through my parents. My sister Victoria and I did a bit of research about microboards, because it was something that was quite novel to us at the time. Right away, I liked the fact that it operates much like any not-for-profit board. As siblings, we liked that there was a great organizational structure which affords some security.

It helps us to think about how to properly make decisions with Jonathan, who obviously cannot make decisions on his own. It provides my parents, who are the primary caregivers for my brother, support so that they don't feel so alone in making decisions. The fact that it is a collective group of family members making a decision and that there is a voting process for certain decisions, forces everyone to collaborate on decisions.

Ray

We met Kelly before ever learning about the concept of microboards. We were part of a group of families that put in a Housing Task Force proposal with Kelly and we were told that a microboard would be a great benefit to help us better manage our funds and administration. We were told that we'd be able to engage our support workers better, manage our home and residential supports, and interact in general with the different trusts we had, such as the RDSP and Henson trust. What we benefited most from in the early days, when we attended family support groups, was the learning that we were not alone. There were a lot of other people out there that were experiencing some of the same challenges as we were.

Victoria

At first, my parents asked us to attend some seminars to learn about microboards. I just feel a lot of that early information went over my head. I've got a lot of information, about the microboard from my parents, from what they told me, and from what Kelly would tell us in the meetings. I think that was most helpful for me.

Who has helped you along the way?

Andrea

Kelly has been really instrumental in helping guide us through the microboard process from the beginning by providing us with a lot of information via emails and links. She never actually told us "This is what you have to do, for example. She was always just there in a

supportive role and enabled us to make our own decisions and figure out how we wanted to structure the board ourselves.

Ray

Having someone like Kelly to support us – helped us put things more in perspective so that we have a clearer vision of which route to go. It's an individual decision. It may not be for everyone. I say that only because not everyone would be willing or able to undertake some of the work that might be required. Having guidance on what action to take, how to get organized, and really go after doing something -- that impetus certainly helped us form a microboard.

How has the microboard changed the way you work together as a family?

Andrea

I think before we had a microboard we were always quite collaborative as a group, but we were unorganized. The microboard enabled us to become more organized about our thought processes. It really just gave us that structure -- that ability to know how to plan it out properly and know what kind of resources we actually had and needed.

It has helped us to have structured meetings. When you are on any board, you have to have annual meetings. There's a ratification process. It's actually quite formal. For us, because we're such a close-knit family – we just have family members named as Directors on the board. We believe, at least in our group, that we are the best decision makers for Jonathan. I think that it's something that's quite necessary, especially dealing with Jonathan who has more extensive needs.

When we get together and we have our annual meetings, we always set out a timeline, and plan and look to the future in terms of what Jonathan's needs might be. It's a real dynamic process. It's not static because just like every other person, Jonathan's needs are constantly changing. We have two in-person meetings every year. We always collaborate and talk about what Jonathan's needs are at that point, and into the future what he might need.

The microboard process forces us essentially to look at decision making for Jonathan now, in the near future and in the far future. This gives us the security of having a direction and yet, we are all aware that it's something that's dynamic that can change over time. After only three years we already have started that process of succession planning.

I think the microboard has benefited Jonathan markedly in terms of offering structure because even though my parents did an amazing job with Jonathan in terms of setting up a routine, the microboard process, offered us the ability to come together and discuss what Jonathan could achieve beyond what we have already planned for him.

Alvin

Jonathan is a big part of the family and my wife and I are the furthest away from him and so looking long term, just from an emergency management perspective, we need to look at moving closer to where he lives to make it work. The microboard helped us understand that it's time to get to know and feel firsthand what's going on. Especially when I think back to that one time where the elevator broke down in the middle of the night and we drove up to where Jonathan lives and we're like 'Ok what do we do?' And, you know, just troubleshooting stuff like that helps in the long run. There was a lot of panic in that situation and we needed to experience it firsthand.

What roles do the different microboard directors play?

Andrea

All of the Directors have a different role and it works out really well because we all contribute to the microboard within those roles. Although, that's not to say that we can't contribute and provide ideas for areas for which we are not responsible. For example, Victoria is responsible for assisting with the social aspects of Jonathan's life. That's not to say that I couldn't contribute to that aspect of his life as well even though I've been assigned the role of secretary.

Imelda

Now that Jonathan has a tracheotomy and a G tube we look to Victoria as the nurse to help us with the decision making and the choices we need to make. We have a good blend on the Board. As a Lawyer, Andrea comes from a different angle and has a different skill set that is assistive.

Victoria

My role is to help Jonathan to work on the social activities and that aspect of his life, however I'm also starting to learn more about the financial/Treasurer role. Because I am a nurse, I also produce videos for teaching new staff how to care for Jonathan, how to take care of his trach and G tube...It is very important to properly orient and train the staff because they come and go all the time and we need consistency in how these skills are taught.

Alvin

Recently with Jonathan's illness, I learned just how big an impact that is from the microboard perspective. We were working on succession planning and putting things in place, so that Jonathan's life would be a lot easier. However, with his illness all of the previous orientation training got thrown out the window. It is like an evolving structure now that his situation has changed. I find that interesting because it always keeps you on your toes and I am someone who doesn't like doing the same thing every day. Seeing a lot of differences and seeing how we have to let things evolve is great, but it is also a lot of work. I find it really amazing seeing how all of this is being pulled together.

How do you involve Jonathan in decision making?

Imelda

We don't really know how much Jonathan understands, but we know he shows his emotions. He shows that he is happy and he definitely tells us when he is unhappy. When we are discussing all the points of view, we are careful to watch Jonathan and he responds like he is trying to communicate something. Jonathan has a certain level of understanding. When we make decisions, we make sure he is there in the room, we watch his body language. He may look tense if he's not happy or more relaxed if he's more at ease. He just cannot communicate with us verbally.

I will give you an example of how we interpret what he feels about a decision. We thought of moving and having Jonathan get a condo of his own so he would be independent with the support of caregivers overseeing him. We would have visited him every day and we thought he'd manage that. He would have a roommate as well and so we were talking about that. He was listening to our planning and we thought he probably understands. Then for about a good month you could tell that he was really unhappy. He didn't like the idea. He was very, very quiet. He would not say anything, and he would not smile. He would just be there and show no emotion and no reaction.

We decided to stop talking about that plan and so it didn't materialize. When we started talking about renovating the basement as a self-contained unit, he became interested. We live in a bungalow and we started planning for that. Once I started buying equipment and putting in a ramp in the backyard for a separate entrance everything changed. Can you believe it, he started beaming, he started to perk up and smile. He showed us that he felt that we included him in that conversation. From that experience, I learned that his feelings are very strong, and that he has a way of showing it too. Being close to him, you see him every day and we can detect what his emotions mean.

How has everyone in your family benefitted?

Ray

The microboard has helped us immensely in being more organized -- no question about it. More disciplined and organized.

Victoria

Before we started the microboard, I knew that eventually, my sister and I will have to work together to look after Jonathan. It's a lot of responsibility. It's good to have the microboard in place. We are building capacity over time. It makes me feel a little more secure about the whole situation because now it no longer feels that it is just all in my head. I don't feel that it is only me thinking about it, now we talk about it together.

I notice that during the meeting itself I usually don't think about asking the right questions. It seems like it is right after the meeting I start thinking about things to ask my parents. The

meetings are definitely a jumping-off point for the conversations that I have been longing to have.

When we're in the meetings, I can feel my parent's sense that we're going in the right direction and they are happy about seeing us learning about what it takes. It is such a relief that we're having conversations about Jonathan's future. We take the time to talk about how we're going to look after him and what's involved in his care. I'm not just having that conversation with my parents, but also with my sister, her husband and my husband. Everybody is involved. Even though as a family we get together every week or every two weeks to visit, these topics don't come up.

Andrea

As siblings we now have families of our own and it's very nice to be together more often, beyond just dropping in. It's another way for us to bond as a family, which is nice.

The microboard really did open Jonathan up to different possibilities for his quality of life. For example, Supporters began taking him to the mall on Fridays so that he is socializing with people other than his workers. This allows him to meet other people -- strangers -- in a friendly environment with the support he needs. He has also started going to out to watch a show or a live performance. I think in those ways, the structure allowed us to think outside of the box. It actually enabled us to come together and brainstorm about what we could do to help him live a fuller life and experience different things.

Kelly

Each family member approached their role from different perspectives, and they all come with strengths and gifts that are so unique. One person may be really skilled with technology and the other one has resources/knowledge and connections with transportation. I mean, it's just a really good team. Everyone shared their strengths and shared a common sense of purpose.

How has the microboard helped with succession planning?

Alvin

For me as a brother in law, I would go over and hang out with Jonathan, but I didn't really pay too much attention to what was happening in his life and what made it work. Now since I got involved on his microboard, I realized that there is a lot of work, even a lot of stress behind the scenes. It makes you appreciate, all of the hard work that everybody puts into just keeping everything in Jonathan's life going. Doing succession planning is way better than just getting thrown into it without having any background and no knowledge and then all of a sudden here you go you are responsible for him. I'm not a big "throw him to the wolves" kind of person. Just getting to know the ins and outs of what takes place in his life and just having that general knowledge is crucial.

Imelda

I think my daughters have a feeling that they're not alone. At least they have each other when we're gone, to continue on with Jonathan's care. We are working on putting all the procedures, all the information about Jonathan in one place on a Google drive so that everyone knows where to find all the information and steps in order for Jonathan to be cared for.

Ray

I like the idea that the girls are picking up little bits and learning a little at a time -- that's like building blocks. That's how you progress. You just have to chip away at things so that it is not overwhelming. We have a Google Drive that we set up, which was set up by Victoria's husband Alvin. It has 11 different sections with meeting agendas, board minutes, contact information, his needs and his services, corporation and the bylaws of the corporation, finances and budgets, food and nutrition, health and medical information, safety measures, life plans and goal setting.

Jonathan's Support Workers are employees not contract staff. We learned from an employment lawyer what constitutes a contract worker versus an employee. We figured that from a legal point of view it is best for us to have them all as employees from a liability point of view. With having a microboard and hiring rather than contracting the staff, there is more accounting and record keeping. There is more overall accountability in place, because we are audited. We have to go to the accountant as a corporation, and they have to file a submission every year to the government.

Kelly

I remember when we were first talking about creating e-learning videos to reduce the time that was spent training new support persons to prepare Jonathan's special diet. We considered this a necessary step, in terms of succession planning and figuring out how to make staffing approaches consistent. But it really felt like it was a longer-term goal and would take a lot of time and commitment. Six months later, Victoria had already created the training videos. The other thing that is amazing to witness is how creating a microboard seems to help families to become more connected and feel stronger together.

What would you say to families who are just getting started?

Andrea

I think that from the beginning, of course we were hesitant as most people naturally are when there is something new and were wondering: "What is this all about?" When you dig deeper and amass more information, we thought it's worth a try. If you don't try something, you're never going to make mistakes, and you're never going to learn from it.

There are definitely growing pains within the first year because we were trying to figure things out. It's just like working with starting up any other organization. However, once we got the hang of things and realized that we could structure it however we wanted that the form was up to us, that the onus was on us to structure it the way we wanted, it actually went smoothly from there.

Ray

Setting up the microboard, at first was very ominous, but now we're starting to feel a little more confident. It's a gradual process and it is not something that happens overnight. It takes years, and it will never be perfect. In other words, a transition is never smooth. But what you aim for is to have as few hiccups as possible on the way. We can see it progressing very nicely right now. When we're gone, at least we will be going with the satisfaction that Jonathan is well taken care of.

It's important when you take on something new that you have some vision and keep in focus the benefit versus the risk. I think that's the way to look at it. In fact, that's what we tried to do. The question is, does the risk outweigh the benefit? Everyone is resistant to change. Let's face it. I think it was John F. Kennedy that said "Change is a way of life. And those who look only to the past and present are certain to miss the future." You have to look to the people around you to help you make decisions, make you see that vision. It makes a big difference.

Imelda

If you are looking for a Facilitator to help you look for someone, of course, who has a lot of knowledge, always positive, someone who is very patient and can really relate to the family. And of course, they can't start without knowing your loved one. They have to put themselves into his shoes. They have to bear in mind that, even though "It's a lot of work" you have to put your heart into it. You have to set aside time for that.

Kelly

Be proactive- As a planner, I'm very proactive. It makes me super uncomfortable to have to be reactive to something rather than thinking out all the possible options and all the consequences. I find the families that really seem to embrace the idea of microboards are also very proactive, rather than reactive. They cannot rest until they know there is a plan and what the future may look like - based on their vision. Being proactive and starting - even if it feels overwhelming- allows you to control your destiny.

Alvin

At the end of the day, you have to put yourself in the persons' shoes. What does Jonathan want and need? I mean, from my perspective, you know, as long as it benefits Jonathan, then it makes it worth it. At the end of the day, it's not for us. It's for Jonathan. Whether it takes a lot of work, a little more work, as long as it works out for him then everything is worth it.