

The Dan Steeves Story

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Three years ago, Dan started a support circle in his efforts to learn more about how to bring people together and talk about what matters to him in his life. From the very outset, he and his family have intended to transform the support circle into a microboard, they are now well on their way. Here is Dan's story. The interview is with Dan Steeves, his mother Dianne Eby, sister Michelle Eby and Diane Peacock his Independent Facilitator.

Dan:

We started when Diane came into my house and said, "Hey have you ever thought of having a support circle before?" And I said, "No". Diane said "Well I'm willing to help you with that." So that's how we got started. I guess at first, I needed to find out what a support circle was, because it's my life.

Diane:

All of his siblings have taken an active part in Dan's life when he was younger and over the years, they have helped to provide support to him even though some live far away. As Dan began facing big decisions in his life, he realized how much his siblings care about him and he wanted a different sort of relationship with them because his paid support was reaching a crossroads.

Dan:

My parents are getting older, so we decided to start a support circle so that someday a microboard would be in place for when they can't be here. At first my question was, how do I know the difference between when my siblings are there in my support circle and when they're just a sibling.

Michelle:

As a sibling, I remember when Diane introduced us to the idea of microboards and Dan and the rest of the family said "Yeah were in. Let's start slow." Diane suggested that we begin by forming a support circle first so that everyone can gain practice and understand their role in helping Dan get stronger in terms of having his say and making decisions.

We got to the point where we realized that our parents are sometimes overwhelmed just with the day to day care. My mom's always been a really great advocate for Dan. She's really good at navigating the crazy waters of supporting Dan and getting him everything he needs, whether it's a wheelchair van or a bath seat or anything that he needs. But then, as siblings we raised the question, what if something happened to mom and dad and they weren't there to support Dan in this way? We were concerned and we realized that we still had a lot of work to do for helping mom and dad answer that question.

Diane:

Strengthening his voice has been important to Dan. He wanted to be heard and understood. At first, just formalizing the intention to get together regularly seemed to heighten everybody's ability to be much more intrinsically involved than they've ever been before, even from a distance.

I think that's why Dan and his family decided to create a support circle because it brings everybody together at a specific time for the purpose of supporting him and finding out more about what he wants, what he needs and the role each of the different agencies play in his life. This was important because everything was kind of disjointed and not everyone really knew what was happening in Dan's life on a day to day basis.

Dan:

Diane, I think you will agree that our first support circle meeting was kind of all over the place because my siblings weren't sure what we were doing. Diane as the Independent Facilitator, you kind of had to coach them along the way and say, "Ok this is what we're doing and this is what we need to achieve."

Diane:

A hundred percent. People were asking what are we doing? It was messy. They wanted to know where to start. They wanted to know why they would do this. It wasn't until we were together for a while that people got much more engaged in a different way. I think that exploration and questioning was heartfelt. We needed a lot of conversations over time to solidify a direction and purpose.

Michelle:

I think the first few meetings were disjointed. I've worked closely with Dan, probably closer than some of the other siblings in a support role just because I'm more local than the others are. That means that I know the terminology, the different things that Diane was talking about in those first meetings.

For me, it was kind of cool to see everybody come to an understanding of why we were meeting and what we were going to do to further support Dan. It's been a really positive time having everyone begin to better understand Dan's world and what he is up against as an adult.

Diane:

We started by having conversations together and then it just kept building from there. Those conversations did not necessarily mean that we would gather together physically in a room, but that we would start connecting people by video conferencing. We also would use email to connect. From the beginning, there was a commitment that Dan and his support circle would meet together at

least four times a year. We wanted to have scheduled times so that we create real intentionality around gathering. In between the regular meetings we found that all of us stay connected in different ways.

Michelle:

The questions that Diane helps us talk about gives everyone on the circle an opportunity to think about things they've never thought of before and to see how we can all be connected through long distance to provide the care that Dan wants and needs.

We started by identifying how everyone has a role to play. One member is involved more with finances, if we have concerns or questions about that. One member helps more with the physical accommodation challenges. Just the other week our brother Jonathan repaired the bath seat that broke. One member understands the different health care and developmental disability systems. Some of the members are really good communicators and they are who Dan goes to if he needs emotional support because they're good at listening. So, now everybody has a role.

Diane:

When we started forming the group, we took the time to recognize the gifts of everyone on the support circle. Because of taking that time, it is beautiful to see how people feel valued in Dan's life and know that what they bring to his circle is unique. The circle is made up of people Dan wanted to invite and not just family members.

Dan:

I will say that before doing this I was worried. I was afraid to let someone else give me advice. I was really close minded to the idea because I was afraid to let someone else in. But Diane set my mind at ease. Not only for myself but for my family. She has a calming way of putting things. I think I was a bit insecure because I'm dependent on everybody for everything.

Diane:

Your voice was clear from the beginning about the uncertainty you were facing. Why wouldn't you be concerned, you're a young man who's trying to figure out your future. Now, I feel there is a sense of shared responsibility, a shared power within your circle. A feeling that everyone is relieved that it's not just on your mom and dad's shoulder. It's not just on your mind and not just your worry.

Michelle:

I can remember shortly after one of our first meetings, I spoke about how when we were kids growing up, our parents implemented this thing called the "family bank" which started as a box of chores that we could choose from as a way that

we could make money. Over time as we grew up, it turned into a support system for our entire family. If one of us needed help we would all pool our money together and help pay for it. Whether it would be helping out with tuition or helping put together a down payment for a first house.

Our family is really amazing at supporting each other. When mom and dad were wondering “why would we invest in creating a microboard?” I said, “just think of it as an extension of the family bank. Dan hasn't really benefited from our family bank because he was the youngest, I don't think he was even around yet when we first started the bank”. Then I said, "this is Dan's family bank because we all need to be there to support him for whatever he needs once you cannot do it anymore."

Dan:

My dad always reminds the family that our family has grown stronger since I came into it.

Michelle:

Yes, it has because we've all had to pull together, right Dan?

How do you go about making decisions within the support circle?

Diane:

We make sure that decisions are shared among the circle and Dan is fully engaged. I will give you an example. Dan has an accessible van and it became clear to everyone that it was on its way out and needed to be replaced. The support circle was really instrumental in coming together around some significant decision making about replacing the van. At first, everyone began fundraising. Then the support circle made a decision not to proceed unless there was funding from March of Dimes so that the expense of the new van wasn't a burden to the family. Before coming to this decision, the worry of it all was on the shoulders of Dan and his mom and dad and that was tough.

Michelle:

Making a collective decision and figuring out a plan in the support circle is interesting because we are all so different. We each bring different things to the table. It was really neat because when we had to help Dan decide about the wheelchair van my brother Ben emerged as our finance guy. He came in with all the logic on the financial side of it. I'm more heart than I am head. I would say “why do the funders make it so hard to get a wheelchair van that he needs?” My other brother, who's very logical, would have us consider “can't we fix the one that we've got” because he is mechanical and more hands on than the rest of us. Stephanie is the part of our team who understands the system and she's really

good at thinking outside of the box. It's neat to see all of our perspectives and how everyone's gifts come into play.

Diane:

We do our best to meet ahead of time to talk about an agenda. Dan is a natural leader and he leads from that. And everyone is very respectful of that. I really believe that nobody tries to take over. We have a real sense of shared power. I think this circle truly believes that Dan's voice is the most important piece. I see that by the respect, the quietness, and the fact that no one is talking over him.

Dianne (mother):

Dan has a sixth sense. And if he feels that somebody is going to be talking over him and trying to make decisions for him, he steps in and he takes control, to make sure that he is still in control. And an example of that was last fall when we got together and there had been some concerns about how to figure out where we will live when he can no longer live with us. We tried before to broach that conversation with Dan at different times. It's upsetting for Dan because everything is so unknown, and he doesn't know what to expect.

A meeting was about to start and he sensed that it was going to be talked about and so at the beginning of our meeting, he just started off with, "I've been doing a lot of thinking and I think I need a two to five year plan." Then he starts talking about his ideas around long term housing. He takes charge and speaks up. It takes him a while to process things and kind of know what he wants or what he thinks about it. If Dan raises the topic then it's a lot easier. I think as a family, we've learned that we have to be sensitive to that and give him time to process each decision and have him take the lead when we are discussing things.

Diane:

Having everyone in person and online in the same room at the same time helps make sure that everybody is piping in and taking part. We all make sure that Dan is really part of those conversations and being able to say, whoa, just a minute.

Dan:

I know what Diane is saying there. I think she's quite good at facilitating, but I do feel like she's also really good at building those relationships as well. It can't be all business. If you know what I mean? It can be fun.

Dianne (mother):

Diane you are amazing at stepping back and just assuring that it's Dan's voice. And, you know, you hold a lot, you care a lot, but you are incredibly respectful and believe that that's where the power should be. I think the sense of humor and lightness is important. When we get together it never feels heavy, it feels quite light and enjoyable. It's a real sense of community. We always have so

much to catch up on when we start a meeting. We build on the positivity of the whole. People like to know that everyone matters in the group. Meetings have a feel of celebration and excitement as well as getting something done.

Diane:

I would like to say that as the facilitator, I feel it is my role to go at the speed of the group and not have my own agenda. I have to keep that always in check. I have to really honor the strength of the group and ensure that the roles and tasks are shared among them.

Diane (mother):

I think it's really good to have an outside source to guide us, especially in setting up the microboard because we don't understand all of the legal aspects of it. We definitely have needed some help in going in the right direction and making the right decisions. We want something in place that's going to be there and be strong for when we're not here to help with making the decisions.

Dan:

Having a circle means that I don't worry as much. I host a talk show on YouTube and I am an advocate for those people who don't have a voice themselves. And my YouTube channel is a way that I can be heard. My support circle believes in me.

Dianne (mother):

We want to help Dan figure out some housing options. That's one of the reasons for forming the microboard, because we're busy with day to day activities and doing everything and sometimes we don't have the time to think long term. The microboard focuses us on how we're going to plan for long term.

Michelle:

As a sibling, I'm just grateful that when the time comes, I can have support from others even if I take responsibility for the main aspects of Dan and his care. I know I won't be alone in it. I would hate to see Dan stuck in a situation where he would have to live in a closed environment, like a nursing home. The microboard helps me do something about the greatest desire in my heart because it is actually a reality that none of us will have to do it alone.

Dianne (mother):

Coming from the perspective of a primary caregiver, starting a microboard has provided me the peace of mind to know that there is a group of people that are there that have Dan's best interests at heart. They care about him and love him and will step in and do the job even though it takes a whole microboard to replace me. It's a safety net there for him and so I know he's not just alone. He's in a vulnerable position and can't always advocate for himself. Even though he's

a really good advocator, he needs help. To have other people there advocating and helping, even now, as I'm still the primary caregiver, is a big sense of relief.

Michelle:

As a sibling, I think it's just a beautiful thing that we can all come together and support, Dan. And the job is not just falling on one of us. It's a group effort and we're going to be there for Dan in the long run. Having Dan in our lives has really brought us together. Working on building a microboard enhances our efforts. It helps us come to know we have ways to keep working together. I think that's a really beautiful thing.

To learn more and hear more from Dan, follow the link below to his YouTube channel entitled Possibilities: We're Taking the Dis out of Disability!
https://www.youtube.com/channel/UCGoPICQhjNJTfu28WhVL0BQ?view_as=subscriber