

Hi, my name is Nancy Gardner.

I live in East Bridgewater, with my husband, Jonathan, and my other son Eric. I began researching Guardianship when Jonathan was 16. The school special education director recommended full guardianship for Jonathan so I was happy I had educated myself on other options. My vision for Jonathan has always been to have his voice heard and allow him to guide us in his journey. Jonathan calls me his safe person. Together we decided to do supported decision-making instead of guardianship.

When Jonathan got Cancer, thanks to SDM I was able to help him understand his options. When he was unsure if he wanted to continue with the treatment I worked with his team to come up with a new plan that he liked. Jonathan then decided to continue with treatment.

When we started treatment no one seemed to know about SDM. I had to explain that I was not just a parent I was a support person and both my husband and I were support people therefore Jonathan needed us both with him to go for treatment. There was pushback at the beginning, I had my forms with me even though I don't think anyone knew what they were. Once I told them I could contact my friend at Disability Law Center about SDM they seemed fine with both my husband and I supporting Jonathan. Once they got to know us it was not a problem. Covid did make it harder. I just think the medical professionals do not know about SDM so therefore they were taken back a little. If there was an SDM law in Massachusetts this would not have been so hard and more families might be willing to try SDM because they would be assured that the agreement would be respected.

One way sdm has supported Jonathan was when we first began working with his oncologist. Jonathan said he wanted to leave the room while the doctor was talking. He said my mom will break down the information for me. The Oncologist explained to me, then Jonathan came back in, and with the oncologist there to guide me, I was able to break it down for Jonathan to help him process all the information.

I think SDM should be law so more people can use it. Families won't have to fight like we had to explain what SDM is to so many health care providers. It will just be understood and accepted. We would be able to say here is the law that says I am allowed to be Jonathan's supporter and I can be with him to provide the support he wants. Cancer was hard enough to deal with, families shouldn't have to fight to get support they need.

Nancy Gardener