



Supported Decision Making in Real Life!

Caroline Nelson, Parent

When I remember my son at 16 and 17, many things come to mind: his love of politics and travel, his curiosity about different world cultures and diversity within our own country, civil rights, marriage equality, sports – the games themselves and issues of ethics within the NCAA, doping and the behavior of professional athletes within intimate relationships. The list of his interests and curiosities – then and now – goes on and on.

I also remember having to coax him out of the house due to mental health issues, to bargain with him about one mandatory outing per weekend, learning to use hair clippers myself so our one mandatory outing wasn't wasted on a haircut. I remember struggling with well-meaning educators, some of whom knew exactly how to reach and teach him on his true ability level and others who expressed doubt that he would ever be able to independently handle a community money transaction because he shut down every time they attempted to count coins. And it was all true: he understood supply and demand, but he couldn't count change.

As his 18th birthday approached, a number of people asked me, as if it were a given, if I was working on his guardianship. I said no. I recognized his need for support in handling adult-level financial and medical decisions, and I certainly worried about his level of independence which was so hampered by his mental health and illness. But I also saw my bright, engaged boy who was excited to vote, who was afraid of girls (because, ultimately, he had an interest in them) and who was thoughtful and open to suggestions as long as we presented them in a non-bossy way that felt respectful of his growing autonomy.

I resisted the idea of a guardianship because I felt I couldn't take his adult decision-making rights away. Although I worried about his ability to predict or handle "real world" consequences of potentially faulty decision-making or the potential for being taken advantage of in a bad mental health moment, I felt that I could support his understanding of his options and remain present or near his decision-making opportunities. I could help protect him to the extent I needed to while shifting the ultimate responsibility for the final decision to him. In the end, I felt it was better for his mental health for us to express the confidence in leaving him with his rights than it would be to choose the possibly safer option of a guardianship.

I knew we could set up powers of attorney to accomplish a lot of what we needed. But as a lazy non-practicing attorney, I opted instead to draw up a private contract – an agreement between our son and his parents that invited us in to assist with decision-making but that clearly left him in the driver's seat when it came to the final word. At the time, just two and a half years ago, this was unorthodox. The

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school honored our agreement, though it was not something they were accustomed to seeing. We crossed our fingers that we wouldn't run into a snag at the bank or in a hospital. It felt right and risky at the same time.

In the meantime, unbeknownst to us, the Texas legislature was working on legislation that would codify the legitimacy of an agreement like ours, and in the winter my son turned 19, the Arc of Texas came out with a model Supported Decision-Making Agreement. The SDMA accomplished everything I was originally looking for. While any SDMA is customizable to the individual and the situation, the Arc's model covered every contingency that was important in our case. In the SDMA, our son and we (his parents) agree to the roles we will all play in his adult decision-making. The SDMA clearly states that our now-20-year-old has complete and final decision-making authority, including the right to nullify the agreement or "fire" us as his supporters. It clearly gives his permission to third parties for us to help him understand the decisions in front of him, to communicate his wants and needs and to interact with professionals. Our son has given us a blanket FERPA release and HIPPA release so we can have access to his records and information. And – the Arc's model form contains language citing to the new statute, so a doubting educator, banker, medical professional or anyone doing business with our son knows they are relying on a legitimate legal mechanism.

We all three – my son, his Dad and myself – carry a paper copy in our wallets, and we have used it on the spot with third parties who don't know us in addition to giving it to all of our son's providers and educators to have on file. It has proven to be the mechanism we need to both ensure his autonomy *and* our ability to help.

And... it satisfies the lazy non-practicing lawyer in me – who understands the legal ramifications but hasn't gotten to the Power of Attorney part of the to-do list yet.

For more information, go to:

[https://www.thearcoftexas.org/wp-content/uploads/2016/06/Supported Decision Making For Families UPDATED Jan 2016.pdf](https://www.thearcoftexas.org/wp-content/uploads/2016/06/Supported_Decision_Making_For_Families_UPDATED_Jan_2016.pdf)

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