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November 22, 2021

The Honorable Adam Gomez, Senate Chair  
The Honorable Michael J. Finn, House Chair  
Joint Committee on Children, Families and Persons with Disabilities  
Massachusetts State House  
Boston, MA 02133

Re: Written Testimony on S 124 and H 272 – Supported Decision-Making

Dear Chairs Gomez and Finn and Members of the Committee:

My name is Malia Windrow-Carlotto, and I am the mother and ex-guardian of my son, Cory James Carlotto. I am writing you in support of Senate Bill 124 and House Bill 272, which would formally recognize Supported Decision-Making in Massachusetts statute.

People on the Autism Spectrum may need support making decisions about finances, health care, and other issues. Such was the case with my son. As Cory was approaching the age of 18, my husband and I felt that he needed more time to develop his decision-making skills. This left us with a dilemma: How do we protect him in the meantime? Do we ask the court for guardianship and deny Cory the rights the law provides him at 18? We researched our options and spoke with human service agencies, lawyers, and trusted friends in the special needs community. The options were presented to us in a binary way -- guardianship or no guardianship. We wanted to protect Cory as he matured, so we chose guardianship, with the intention that one day we would ask the court to give Cory his rights back.

We were shocked to learn that it would cost us thousands of dollars in legal fees to obtain guardianship. On top of that, we were required to publish an ad in the local newspaper declaring that we believed our son to be incompetent and in need of a guardian! Published for all the world to see .... published so that total strangers who had no interest in my son during his first 18 years of life could express their opinion about how we raise him for the next 18 years! We didn't think Cory was incompetent. He just needed more time!! We also were required to have him served with court papers by the Sheriff. All of this so that we could continue to raise and protect our precious son! It was appalling to us! Even the Judge admitted the system was flawed. I will always remember his words that very first day in court: "OK, let's get this over, so these nice people can go back to raising their son."

Because of Cory's anxiety and Obsessive Compulsive Disorder, I was not only appointed his guardian, but also his Rogers Monitor for medication. Both of these designations required reports and appearances in the courts on a regular basis. The court assigned him a lawyer who

met with him on an annual basis and reported to the court. It became an endless stream of paperwork and court appearances, so that we could continue to care for our son as we had always done prior to his turning 18.

Guardianship.....I thought I knew what it was all about. I thought it was about protecting and raising our son, but it was so much more. In 2012, Cory suffered an acute bout of anxiety and panic attacks. For 10 days, we worked with his team of doctors, therapist, and the local crisis center to combat his panic. He was frightened, and we were frightened. There was very little help available to us, and it became necessary to consider hospitalization for him until we could find a medication to help him. All of my son's life, I have advocated for him and made sure that everyone knew what Cory wanted. Here I was, faced with making a HUGE decision for him, for us. As his guardian, I had to be the one to make the decision. Hospitalizing him was the hardest thing I have ever done. To this day, the memory causes me great pain. I believed I knew what Cory would want. Only later, when Cory was able to express his feelings about that time, did I learn what he really wanted. He wanted to be asked. I never asked him if he wanted to go to the hospital. I decided for him, and even though he now understands it was necessary, he still states, "But you never asked me." That statement made me realize that my son no longer needed a guardian, just guidance.

In January 2015, our affiliation with Nonotuck Resource Associates through the Adult Family Care program and their affiliation with the Center for Public Representation and the pilot program for Supported Decision Making (SDM) created the perfect storm. Cory selected his father, his sister, and me to be on his support team. In addition to his SDM Agreement, Cory executed a health care proxy and a power of attorney that would be invoked when - and only when - he, his support team, and his doctors feel it is necessary. On November 17, 2015, we appeared before a Berkshire County Probate Court judge, and Cory successfully petitioned to end his guardianship. This was the first time a Massachusetts resident had his guardianship terminated in favor of an SDM Agreement. I could support the court ending Cory's guardianship, because I felt comfortable that the supports that he needs for making decisions are in place without it.

Cory has flourished since he started to use SDM. The SDM Pilot program encouraged Cory to see himself as an adult. He has moved out of our family home and tried different living arrangements, including Independent Living and Shared Living. Cory is currently living in his own apartment in a duplex with a caregiver living on the other side of the duplex. Cory has traveled the country with friends to places he really wanted to see, such as Warner Brother Studios in California where the sets of his favorite TV shows are and to Tennessee to enjoy time with friends. On his journey with SDM, Cory began to be employed, which is huge for Cory with his anxiety and OCD. For each job opportunity, we discussed the pros and the cons and what the full picture would look like with his schedule, and he decided if he wanted to pursue the positions offered to him through supported employment. He started off working 3 hours once a week and now he is working full time.

Cory loves music, movies and spending time with his friends. All of these cost money. During the SDM pilot program, we worked on Cory's understanding and responsibilities about money management. As a son, he looked to Mom and Dad to fund all his interests. As an adult, Cory is learning that he must pay his own way. Together, we have been working on a budget, deciding which things are most important to him, and finding ways to support him to do all the things that mean the most to him in the most cost effective way. I do my best to explain to Cory what his options are, to educate him about his pros and cons, and to know that, when and if he makes mistakes, it is all part of growing up.

Cory is now a 30-year-old young man. He has continued to mature and express his desires and opinions. SDM has brought new dynamics to our family. As parents, we now have to see Cory as an adult, not just our son. And, in turn, Cory is learning to recognize us as his supporters, not his decision-makers. The SDM Pilot Project allowed our son to show his voice to the world and to become the adult he wishes to be, and we as his parents could not be more proud. Cory has even had the opportunity to share his SDM experience with a subcommittee of the U.S. Senate Judiciary Committee! We will always be grateful that Nonotuck and the Center for Public Representation presented us with the perfect storm. You can learn more about Cory's story by visiting: <https://supporteddecisions.org/stories-of-supported-decision-making/corys-story/>.

I want more Massachusetts residents with disabilities and their families to have the opportunity to access SDM and SDM Agreements. Passage of S Bill 124 and H Bill 272 will encourage that. I strongly urge you to support this important legislation.

Sincerely,

*MWindrow-Carlotta*

Malia Windrow-Carlotta