

**Written Statement of Amanda Jo Benoit
Pittsfield, Massachusetts**

For the U.S. Senate Special Committee on Aging

Guardianship, Conservatorships, Protective Arrangements, and Alternatives

March 15, 2023

Hi, my name is Amanda Jo Benoit from Pittsfield Ma. Supported Decision-Making (SDM) is great for me, because I get to make my decisions with help from my team. On my SDM team, I have Maggy, Sandy, Diane, and my mother.

I think SDM helps me, because I look to Sandy and Maggy for support, and if I am with Diane, I will speak to her. I also speak to my mom if I need to too.

My SDM Team has helped me join Karate, and work on my health. I have also had my SDM team help me at the bank and with my boyfriend Joe.

I have been in the SDM Pilot Project for seven years. My SDM Team has helped me with many things.

I now have my Green Belt in Taekwando. I have traveled to many places in the country with my friends, and I am now a World Traveler. I went to London, Paris, and Rome with my friend Maggy last year. In the past year I have gone through some major health changes and major surgeries, and I leaned on my SDM Team to help me understand what was happening to me and what the doctors were saying. Sandy and my mom helped me through each step. They spoke to me and had a one on one discussion and provided me with the big picture of my decision. I then made the decision to have the surgery on my spine, which was needed because I kept falling and loosing feeling in my legs.

In ending, My Voice Matters! Please vote for SDM!

You can learn more about my story at:

<https://supporteddecisions.org/stories-of-supported-decision-making/amandas-story/>

**Written Statement of Cory Carlotto
Pittsfield, Massachusetts**

For the U.S. Senate Special Committee on Aging

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Hi, I am Cory. When Supportive Decision-Making (SDM) was mentioned to me, I liked the idea because it fit perfectly within my life goals to start making my own decisions and choices.

I have always been able to make my own choices. However, my mom and dad have been my guardians for most of my life.

When Nonotuck and CPR came to my house to explain about The SDM Pilot Project, I liked the idea that my sister Carisa could be included in my care and help me understand decisions that will come up. She is the primary one that I spend quality time with outside my parents. I also liked SDM, because my parents could also be a part of my team. I tend to lean on my mom to help me understand decisions that need to be made when I am at home and in the community. My dad is also there to extend his help as well.

On Nov 17, 2015 (my Mom's Birthday), I was the first person in Massachusetts to have my guardianship relinquished for the Supported Decision-Making Model. This moment was very special, because I felt my own freedom for the first time.

Since I have started SDM, I have made some big decisions with my team. I made the decision to go to California and Las Vegas with friends. This was huge decision for me, because I am not a big traveler. However, my friend Maggy approached me about the California trip and the idea of seeing the sets of my favorite TV Show Pretty Little Liars at Warner Brothers Studios, and I could not resist. My SDM Team helped me understand the full extent of the trips and the decision I was about to make. After a long conversation and going over the pros and the cons of the trip, I decided to take the chance and go to California. This was the Best Trip of my Life! In 2022, I also enjoyed going to Las Vegas with my housemate Cliff.

With using the SDM Model, I have made decisions about getting a job and trying different types of living arrangements out. Some living arrangements did not work, and this gave me experience for the next time.

With support from my SDM Team, I have taken more leadership with my medication decisions and have added more psychiatrist appointments if I felt I needed them.

In closing, Supported Decision Making is really important to me. I love my family and they will always be there to support me.

You can learn more about my story at

<https://supporteddecisions.org/stories-of-supported-decision-making/corys-story/>

**Written Statement of James Cowell
Pittsfield, Massachusetts**

For the U.S. Senate Special Committee on Aging

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March 15, 2023

Hi, my name is James Cowell. I live in Pittsfield, MA. I like Supported Decision-Making (SDM) for many reasons. I have been involved in the SDM Pilot Project through Nonotuck and Center for Public Representation since 2018. When Nonotuck approached me about SDM, I thought of my future and how important it is to help me keep my voice. I have used SDM since Oct of 2018 and had my SDM agreement signed after doing a trial period in May 2019. I like SDM because it allows me to choose who I want to help me understand decisions. On my SDM Team, I chose, my mom Marie, my dad Ray and my sister Shannon who is also a person with disabilities.

Since joining Supportive Decision-Making, I have made the decision to start traveling around the country visiting family. I leaned on my SDM Team to give me the big picture of what I would have to do to accomplish my goal. They sat down with me to have a one on one discussion to go over the pros and cons. For this trip I would have to save the majority of the money I make from the Goodwill and spend less. I really wanted to see my relatives in Texas, so I chose to pursue this goal. I saved money for a few months and then I was able to travel to Texas to visit my family.

My SDM Team helped accomplish my greatest goal in life, to see Hulk Hogan at Wrestle Mania. A friend offered me a ticket. However, I needed money for everything else such as travel, hotel, food, and souvenirs. I asked my mom and dad to help me understand what was needed and I went to the bank to take out the money. In this decision, I knew coming back from Wrestlemania things were going to be tight, so I managed for a few weeks and began saving money again.

My SDM Team has helped me so much in achieving my dreams. I love advocating for Supported Decision-Making. I was recently asked to do an interview with Salon, a big time media news source, on how important SDM is. This was such a great opportunity, because they were trying to advocate on different models than Guardianship and Conservatorship in Brittany Spears case. I was happy to advocate for SDM because it helps people with disabilities keep their voice and make the final decisions in things with support from a team if needed.

You can learn more about my story at:

<https://supporteddecisions.org/stories-of-supported-decision-making/amandas-story/>

You can read the Salon article here:

<https://www.salon.com/2021/06/27/the-supportive-decision-making-model-that-might-have-saved-britney-spears-from-conservatorship/>

**Written Statement of Johnathan Jenkins
Dalton, Massachusetts**

For the U.S. Senate Special Committee on Aging

Guardianship, Conservatorships, Protective Arrangements, and Alternatives

March 15, 2023

Hi, I am Johnathan and I like Supported Decision-Making! I have my family and closest friend help me understand decisions and help me pursue my interests. On my SDM Team I have My Mom, Dad, Sister Sam, Aunt Debbie, Aunt Shannon, Grandma and my friend Maggy. I have been at Nonotuck for 14 years.

When I need help with decisions I usually look to my mom and dad for support. However, I also speak to my other team members when they are visiting. My SDM Team has helped me out at my job. I work at Guidos Marketplace and my SDM Team helped me get extra hours. I like to work and make money and I needed help getting more hours and so I had my team help me. My friends at Guido's take care of me at work. I work with my job coach Aunt Shannon and I have worked for Guidos for 13 years. I love it there!

My SDM Team helps me grow in my skills such as with my banking, making health decisions at doctors and dentist appointments and buying healthy food choices. My SDM Team is very important to me and I trust them.

Since starting the SDM Pilot Program, I have made many Awesome Decisions in my life with my SDM Team. I have saved money and purchased a SMART TV and have renovated my room. I have traveled with my friends to many places such as California, Tennessee, Las Vegas, Arizona and Florida. I enjoy going on vacations because I get to see some of my favorite friends like my friend Billy Tobin in Florida.

In Closing, Supportive Decision Making is Important to me because I feel I can make my own decisions and get help from my team to reach my goals. I am thankful for CPR, Nonotuck, My Best Friend Maggy and George Fleischner for the SDM Pilot Program. It has changed my life. I am excited to be the Newest leader in SDM!!!

You can learn more about my story at:

<https://supporteddecisions.org/stories-of-supported-decision-making/johnathans-story>

**Written Statement of Maggy Walto
Western Massachusetts**

For the U.S. Senate Special Committee on Aging

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March 15, 2023

Hi, my name is Maggy Walto, and I am writing about Supported Decision-Making (SDM) from the standpoint of being a Supporter, and a Care Manager for some of the participants in our SDM Pilot Program in Western Massachusetts through Nonotuck Resource Associates and Center of Public Representation.

I first want to start off with giving a Brief History about Nonotuck. Nonotuck was established in 1972. Nonotuck is a value based agency. We have been doing Shared Living for over 30 years, and we have placements across the state that has lasted over 25 years. I have been lucky to be a Care Manager for some of those placements, and the relationship is just so meshed from picking clothing together to planning vacations across the country together. The skills and communication with one another are outstanding. Most of all, it's the love and the compassion that is shown and driven by our values at Nonotuck.

When Nonotuck was approached about SDM in 2013, we thought it would be the perfect fit with our values and the relationships that have blossomed. The Western Mass Care Managers reviewed their caseloads, and we chose a small sample to start the pilot program. I am very interested and invested in SDM, and 7 of the families that were chosen were from my caseload. The Executive Director did meet with most families from the survey to discuss the pilot program.

Through Nonotuck, I am currently a Care Manager for our Adult Family Care Program. My position has expanded with SDM because, additionally, there are different responsibilities.

My Role as Care Manager is to:

- Provide information to families and supporters about SDM
- Attend SDM family meetings with CPR and Nonotuck Directors
- Help SDM participants understand SDM and SDM Agreements
- Assure the participant's voice is heard and the participant is satisfied
- Review SDM Agreements with person on an ongoing basis; notify CPR-Nonotuck team if anything needs to be changed or updated.
- Collect information on SDM when used and participate in pilot evaluations

My Role as a SDM Care Manager has had its benefits:

- Seven Families have gained an interest in SDM and have gone through the process.

- Families have grown in love with incorporating SDM into their lives.
- Families have grown closer and used SDM as a family planning tool.
- SDM Agreement signing night was very special for all involved.
- The Participants voices are being heard throughout the process and ongoing.

As a SDM Supporter, I play a different role. A Supporter is a person who the participant has chosen to be on their Supported Decision- Making team. The participant chooses what areas of decision-making he or she wants the supporter to help them in. The Supporter's role is to help the person understand the decision that is being asked at their learning level. For each of the participants I help support, I have to brainstorm the best approach to help them understand the decision that is being asked, such as:

- One on One small conversation using Pros and Cons
- Repetition of discussion
- Examples at person learning level
- Informed Consent about what actual decision they are making
- Provide them with info on the risks of their decision
- Physical Demonstration. if needed

For example, I serve as Amanda's supporter. Amanda has flourished in being a part of the SDM Pilot Project. She has made big decisions in regards to her job, health, financial decisions and getting involved in Taekwondo. Amanda leans on her SDM Team when needed if she needs more help in understanding a decision. You can learn more about Amanda's SDM Journey by visiting: <https://supporteddecisions.org/stories-of-supported-decision-making/amandas-story/>

**Written Statement of Malia Windrow-Carlotto
Dalton, Massachusetts**

For the U.S. Senate Special Committee on Aging

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March 15, 2023

My name is Malia Windrow-Carlotto, and I am the mother and ex-guardian of my son, Cory.

Cory is on the Autism Spectrum, and, as he approached 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 Cory in the meantime? Do we ask the court for guardianship and deny him the rights the law would provide him at 18?
- We researched our options and spoke with human service agencies, lawyers, and trusted friends. The options were presented to us in a binary (winery) way -- guardianship or no guardianship. We chose guardianship, with the intention that one day we would ask the court to give Cory his rights back.

I thought I knew what Guardianship was all about. but it turned out to involve so much more.

- First off, it cost us thousands of dollars in legal fees.
- In addition, we were required to publish an ad in the local newspaper declaring that we believed our son was incompetent. We didn't think Cory was incompetent. He just needed more time to mature!
- Even after the court appointed me as Cory's guardian and Rogers Monitor, we faced an endless stream of paperwork and court appearances.

Then, in 2012, Cory had an acute bout of anxiety and panic attacks. It became necessary to consider hospitalization until we could find the right medication.

- To this day, the memory caused me great pain. I believed I knew what Cory wanted when I made that decision as his guardian.
- Only later, did I learn what he really wanted. It was to be asked. I had never asked if he wanted to go to the hospital. I just decided for him.
- It made me realize that my son did not need a guardian, just guidance.

In January 2015, Cory joined a pilot program on Supported Decision-Making that was organized by his service provider Nonotuck Resource Associates and the Center for Public Representation.

- Cory selected his father, his sister, and me to be his supporters and as such, I do my best to explain to Cory what his options are, to educate him about the pros and cons, and to know that, when and if he makes mistakes, it is all part of growing up.
- On November 17, 2015, Cory became the first Massachusetts resident to have a court terminate his guardianship in favor of a Supported Decision-Making Agreement.

Cory has flourished since he started to use Supported Decision-Making.

- He is currently living in his own apartment, has traveled the country with friends, and is now working full-time.
- Supported Decision-Making has helped our son become the adult he wishes to be, and I could not be prouder.

Please support federal legislation, so more people can benefit from Supported Decision-Making. Thank you again for this opportunity to submit this written statement.

**Written Statement of Sandy Robinson
Pittsfield Massachusetts**

For the U.S. Senate Special Committee on Aging

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March 15, 2023

Hi, my name is Sandy Robinson. I am from Pittsfield Massachusetts. I am writing in regard to my support for Supported Decision-Making (SDM).

In 2009, I was delighted to have the opportunity to meet a young woman named Amanda who needed a place to stay on Thanksgiving Eve, so I opened my home to her, and our relationship blossomed from the get-go. Amanda was supported by Nonotuck Resource Associates. At this time, I was a single mother raising two beautiful children, Malya and Craig, and God had a plan for Amanda's arrival to our family. She fit right in with the family activities and enjoyed going to church, parties and having family dinners together. As time went by, Amanda needed help finding out where she was going to live. Using her own SDM Model at the time, Amanda reached to her friend Maggy and confided in her and had a one-to-one discussion about her options. Amanda was very happy with my family and our friends, and she decided to stay.

Being asked to be Amanda's Caregiver was TRULY the Best Decision I have ever made in my life. Amanda has opened my eyes and my children's too so much. She helped my children learn more on how to respect and help people with disabilities. She is the core of our family. Our relationship blossomed so much that I asked her to be a Bridesmaid in my wedding.

In 2014, when Amanda was asked about SDM, I thought of her future. This would be the Best Model for Amanda to choose, because it would secure her rights and choices. Amanda knows who is in her life and who she trusts. She is also capable of making decisions. However, Amanda's tends to need moral support from her SDM Team, one-on-one discussions, conversations going over the pros and cons. and getting info on the big picture of the decision. When Amanda met with Nonotuck and CPR about SDM, I was happy she chose to join the pilot, because she made an awesome choice for her future and a decision to secure her skills.

Since Amanda signed her SDM Agreement, she has flourished in trying to achieve her big dreams and work on her independence. She has consulted with her SDM Team on some major decisions, such as her banking, relationships, health, and best of all living her dreams to travel. Amanda has joined Karate and traveled the world to London, Paris, and Rome with a friend and across the U.S. Over the course of the last couple years, she has had to make serious life decisions, and the SDM model really helped her keep her own voice. She leaned on her SDM Team when she needed support and she was able to receive more education around the decisions that needed to be made. At the end of the day, Amanda voice is always being heard, and we are very thankful for Supported Decision-Making.