

Supported Decision-Making

Supporting Youth with Disabilities into Adulthood

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Today's Topics



- What happens at age 18?
- What is adult guardianship?
- Why think about other options first?
- What is Supported Decision-Making?
- What legal tools can be used along with Supported Decision-Making?
- How does Supported Decision-Making work?
 - The journey of Jonathan and Nancy

What Happens at Age 18?

- In Massachusetts, people become **legal adults** when they turn 18
- Under the law, they get to **make their own decisions**, regardless of whether or not they have a disability
- Schools call this “**Transfer of Rights**”



Main Legal Tools for Decision-Making in Massachusetts

- **Supported Decision-Making**
- **Shared Educational Decision-Making**
- **Health Care Proxy**
- **Durable Power of Attorney**
- **Delegated Educational Decision-Making**
- **Representative Payee**
- **Court-appointed Guardian or Conservator**
 - Temporary Guardianship
 - Limited Guardianship
 - Conservatorship
 - Guardianship
 - Rogers Guardianship

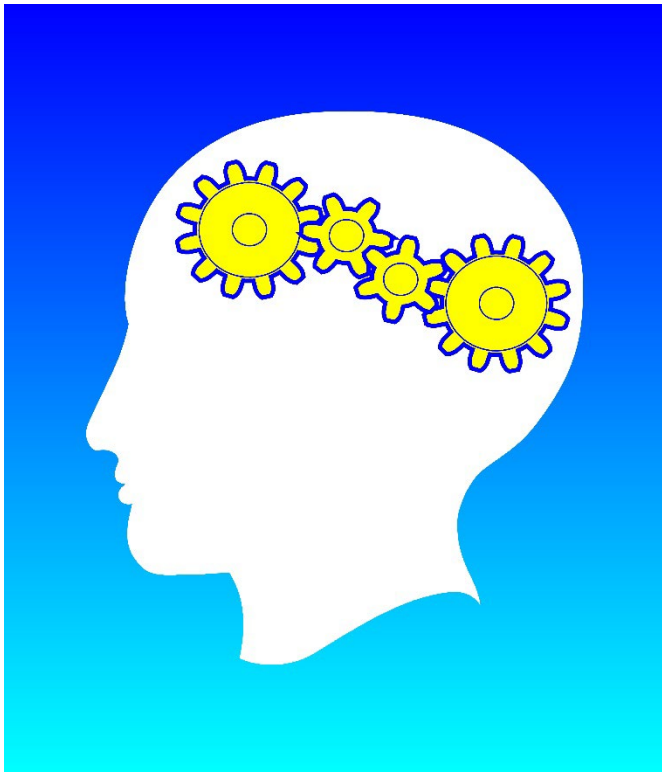


What is Guardianship for Adults?



- A **formal legal process** where a **court** decides an adult is “**incapacitated**” and that someone else (a “guardian”) must be **appointed** to make all or some decisions for them.
- **Guardianship = Court**
- **Different kinds** in Massachusetts
 - Temporary
 - Limited Guardianship
 - Conservatorship
 - Guardianship
 - Rogers

Rethink “Capacity”



- Capacity is not
 - “all or nothing”
 - Based solely on **IQ or diagnosis**.
- People may have the “capacity” to
 - Make **some decisions** but not others
 - Make decisions at **some times**, but not others
 - Make decisions **if they get help** understanding
 - **Pick someone else** to make decisions for them
- A **lack of opportunity** to make decisions can **prevent** people from **developing capacity** or **further decrease capacity**

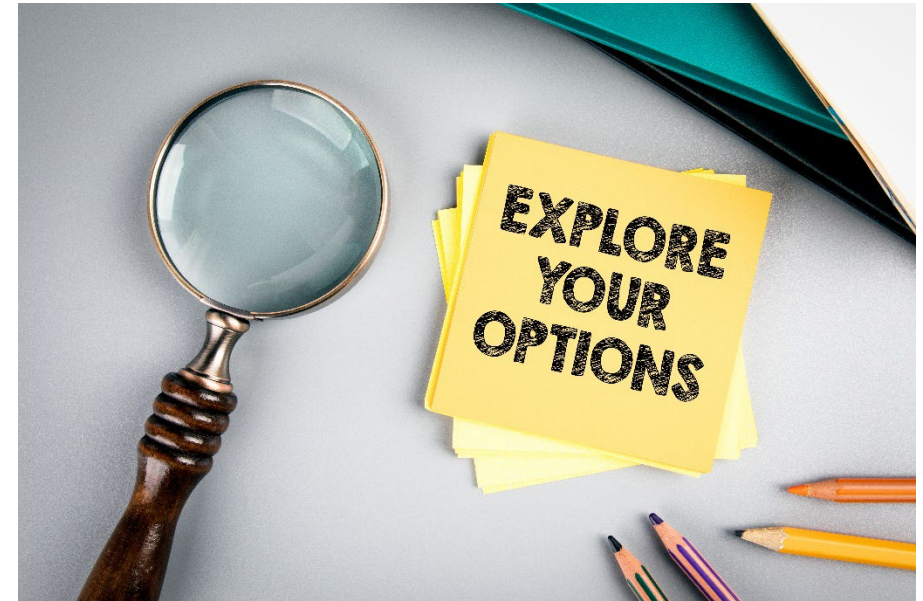
What is Guardianship NOT?

- NOT the **only option** to consider
- NOT just a **piece of paper**
- NOT all powerful
- NOT a **guarantee of safety**
- NOT without downsides



Why explore other options first?

- **It's the law** – Least restrictive alternatives doctrine
- Guardianship can be **time-consuming, complex, costly**
- Guardianship can be **difficult to change or end**
- Decision-making is a **learned skill**
- **Self-determination** is linked to better life outcomes



What are other options?

- **Supported Decision-Making**
- **Shared Educational Decision-Making**
- **Health Care Proxy**
- **Durable Power of Attorney**
- **Delegated Educational Decision-Making**
- **Representative Payee**
- **And MORE**



What is Supported Decision-Making?



“**assistance** from one or more **persons of an individual’s choosing** in understanding the nature and consequences of potential personal and financial decisions, which **enables the individual to make the decisions**, and in **communicating a decision** once made if consistent with the individual’s wishes.”

- See Uniform Guardianship, Conservatorship and Other Protective Arrangements Act (UGCOPAA), § 102 and comment

What is Supported Decision-Making NOT?

- It is **NOT someone else** making decisions for – and instead – of the person.
- It is **NOT** the person making decisions **alone**, without any help.
- It is **NOT** the person making decisions **only if the supporters agree**.
- It is **NOT** “one size fits all”
- It is **NOT** only for people with **certain kinds of disabilities**



Common Questions About Supported Decision-Making

- Is it **new**?
- **Who** can use it?
- **What** does it look like?
- How is it **different** from:
 - Guardianship?
 - Surrogate or substitute decision-making?
- Is it **legal**?
- Is it **safe**?



Common Legal Tools to Use Along with Supported Decision-Making

- Release of information forms
- Health care proxies
- Durable powers of attorney



More Tools in the Supported Decision-Making “Toolbox”

- ▶ **Supported Decision-Making Guides**

- ▶ Visit <https://supporteddecisions.org>

- ▶ **U.S. Federal Law**

- ▶ Americans with Disabilities Act
 - ▶ Section 504 of the Rehabilitation Act and regulations
 - ▶ Reasonable accommodation/modification

- ▶ **National Trends**

- ▶ [U.S. agencies and national organizations](#)



A decorative border made of various watercolor brushstrokes in shades of blue, green, yellow, and purple, framing the central text.

OUR JOURNEY WITH SUPPORTED DECISION-MAKING

Jonathan Gardner
Nancy Gardner

How Did You First Learn About SDM?

- I learned about SDM when I was 16.
- My parents went to a meeting about it.
- SDM means I get to make my own choices.
- I can ask people I trust to help me.
- I liked the idea of having support but still being in charge



Here I am with my Mom, Dad and Brother in front of the US Capitol where I got to testify for a few bills. .

School Experiences That Influenced SDM Choice

- School was very hard for me.
- I was bullied and got hurt.
- My teachers didn't follow my plan.
- I felt like I had no voice.
- When I was homeschooled, I got to make choices.
- I wanted to keep making my own decisions.



Here I am with one of my Friendship Supporters who is also the first person I ever left my house with that was not family after my trauma.

How Do You Pick Your Supporters?

- I picked people who know me and care about me.
- My family were my first supporters.
- Later, I added more people.
- Supporters can change as life changes.
- I only choose people I trust.



Here I am with my Financial Supporter Mr. Stickney. He supports me with all things money.

What Makes A Good Supporter

- They listen to me.
- They don't take over.
- They help me understand things.
- They help me think about what to do.
- They make me feel safe.



Here I am with my Supporter Adam who helps me with Friendship and is also my Wingman. He brought me to my very first live Wrestling event.

What Kind of Support Do You Get From Your Team?

- They help me understand big decisions.
- They give me emotional support.
- They help me look at the good and bad of each choice.
- I make the final decision.



Here I am with Mrs. Clifford who supports me with my Mental Health.

Using SDM During Cancer Treatment

- Cancer treatment was very hard.
- I wanted to quit.
- My mom didn't force me, she supported me.
- We made a new plan with my doctors.
- I kept going because the decision was mine.
- SDM helped save my life.



Here I am on my last day of radiation with my Grammy and Papa who are my Faith and Family Support People.

Where Would You Be Without SDM?

- I might have given up.
- I might have lost my rights.
- I wouldn't feel in control.
- SDM helped me stay strong.
- SDM gave me hope.



Here I am with one of my work/advocacy supporters, Anna. I met her when I was using SDM when I had Cancer. She gave me purpose when she asked if I would testify for SDM .

How Has SDM Changed Relationships?

- People respect me more.
- They help me without taking over.
- I'm allowed to make mistakes and learn.



Here I am with one of my Friendship Support people Miss Nicole. Most recently I just became an Unlce to her daughter Kinsley.

How Do You Choose Supporters?

- I pick people I trust.
- They listen and care about what I want.
- They don't try to control me.
- I asked my friend Morgan to be a supporter because we work well together.



Here I am the day I asked Morgan to be one of my Support People.

What Do You Want Families to Know About SDM?

- SDM means you don't have to do things alone.
- It's about getting help while keeping your rights.
- Everyone deserves respect.
- Even when life is hard, SDM works.
- It gives people freedom and safety.



Here I am living my best life!

Did Anyone Tell You to Get Guardianship?

- Special Education Director said we should.
- He was worried about medication.
- I knew that wouldn't fix things.
- Then I learned about SDM.
- It was a better fit for our family.



Here is Jonathan in our home school room on the first day of 7th grade with me.

What Do You Do as a Supporter?

- I help Jonathan process information.
- I help him make pro and cons list.
- I don't make choices for him.
- I'm here to support, not control.



This picture is Jonathan on his last day of radiation where he put his faith in me to help support and guide him to a plan that was best for him overall.

What Happens If You Don't Agree?

- I listen first.
- I ask if I can share my thoughts.
- We make pro and cons lists.
- Jonathan decides.
- I support him with his decision.



This is a picture of Jonathan testifying at the Massachusetts State House for the Police Training Bill. He had just done a Police training that morning and then had to wait over 2 hours to testify and asked me if I could sit next to him for support in case he needed information processed for him.

Do Doctors Understand You're a Supporter?

- Not always at first.
- Some thought I was in charge.
- I explained SDM and that it is an accommodation under the ADA.
- Now they understand that Jonathan makes his own choices.



This is a picture of 2 of Jonathan's nurses who once they found out that Jonathan needed them to respect his SDM agreement they said they were up to do anything that would help to make Jonathan well.

What's the Biggest Thing You've Learned?

- Support builds confidence and independence.
- I am learning from him every day.
- Jonathan offers me a lot of support!



This picture is from an international conference that Jonathan picked me to go with him as his support person. It was an honor and privilege to be with him.

What Should Families Know About SDM

- You don't have to give up being involved.
- You just support in a new way.
- Your loved one can be in charge.
- You can still be part of their life.
- SDM helps builds confidence and self esteem.



This is a picture of me, Jonathan and our 2 dear friends Sandy and Craig who taught us all about SDM and now we all share our stories together.

My SDM Team



Everything



Everything



Friendship/Girls



Mental Health



Finances



Faith/Family



Wingman/Friendship



Friendship



Friendship



Work and Advocacy

Handouts

1. PowerPoint
 - <https://tinyurl.com/2s362f55>
2. Learn about Supported Decision-Making
 - <https://tinyurl.com/mpcessea>
3. Getting Started with Supported Decision-Making in Massachusetts
 - <https://tinyurl.com/mr3c7rw3>
4. Resources and Forms for Massachusetts Families
 - <https://tinyurl.com/5n7f7f37>
5. Key Words to Know in Massachusetts
 - <https://tinyurl.com/mesnredb>
6. CPR Sample SDM Agreement Form & Instructions for MA Residents
 - <https://tinyurl.com/4h8n6rcb>



SUPPORTED DECISION-MAKING

- Any Questions?