

MASS DD Council & GAIN Coalition Presents:

Unraveling the Mysteries of Guardianship Alternatives
A Community Conversation with those who live it





Massachusetts Developmental Disabilities Council (MDDC)

The MDDC is an independent state agency:

- Funded by the federal government
- Dedicated to empowering people with intellectual /developmental disabilities (IDD) and their families to enjoy full productive lives
- We promote self-sufficiency, community inclusion, and opportunity
- MDDC is part of a national network of 56 Developmental Disabilities Councils (DD Councils) in every U.S. state and territory.



Guardianship Alternatives & Innovation Network

The Guardianship Alternatives & Innovation Network (GAIN):

Facilitated by the MDDC

Focuses on promoting, supporting, and implementing alternatives to guardianship for people with intellectual and developmental disabilities

Includes self-advocates, family members, and advocacy organizations who work to ensure that individuals with disabilities have self-determination rights.

Introducing Key Terms: Betsy Johnson

Betsy will outline key options for decision making such as:

- Guardianship
- Rogers Order
- Limited guardianship
- Plenary guardianship
- Medical Guardian
- MA Health Care Proxy
- Durable Power of Attorney
- Supported Decision Making



Beth Kollett





Craig Kinney and Sandra Heller

Supported Decision Making & Alternatives:
HealthCare Proxy
Power of Attorney

SUPPORTED DECISION-MAKING

Supported decision-making (SDM) promotes:

- Self-determination
- Control
- Autonomy
- Independence



HOW DOES SDM WORK?

- Individuals with a disability receive necessary supports to make a decision on issues - big or small - affecting their lives
- Individuals choose one or more trusted people to assist them to make decisions - friends, family members, relatives
- Relationship between individual, supporter is built on trust and commitment
- SDM recognizes that will and preferences are the core of decision making abilities
- SDM is consistent with concepts that people may be competent in some areas even if not in others





PERSON CENTERED PRACTICES THAT ALIGN WITH SDM PRACTICES

- Social Inclusion
- Person centered planning
- Upholding human rights
- Self-determination
- Circles of support/intentional networks
- Targeted individualized support
- Least Restrictive practices
- Use of natural supports



DECISION SUPPORTER ROLE

- Supporters and individual with a disability discuss possible decisions and the ramifications of those choices/decisions.
- Individual with a disability reaches his/her own decision.
- Supporters honor/respect individual's decision. No requirement to agree with a person's preference or decision.
- Where necessary, supporters help to communicate the individual's decision to involved community members.
- Respect, hard though it may be, person's right to make a "bad" decision
- Honor the "dignity of risk" – the person has the opportunity to try new things, to test limits, to discover capabilities
- Acknowledge the risk of falling, of failing ...and the courage to persevere, to keep trying





Hi my name is Craig Kinney. I am 37 years old and I have Down Syndrome. I live in my own home with a roommate. I have a Supported Decision-Making Agreement, a healthcare proxy, and a power of attorney. These papers help show people that I make my own decisions, and my supporters help me understand. My supporters are my mom, my sister Kathryn, Chris, Jonathan and Nancy. They help me think about choices, but I decide.



I had big medical decisions too. I had tracheostomy for 5 years and many surgeries. Even when I couldn't speak, my supporters explained things to me. Sometimes I needed to hear things in my mom's voice. They helped me understand what the doctors were saying. I always got to make the final choice.



SDM is like using a GPS!!! It helps me understand choices I make. I drive my own life.

For example, I choose where I go on vacation, activities and how I spend my money. I make my own decisions.

My supporters help explain things I don't understand. But I decide!! And if something doesn't go right, I try again.



I started using SDM when I was a teenager. Back then, we didn't use the name "SDM", but I always made choices with help from people who understand me. Later, I signed a formal SDM Agreement through a pilot program. It made what we were already doing official. A good supporter gives me choices. They talk clearly. They help me stay calm and understand things. Any they respect what I want. My family is very important to me. My mom never wanted guardianship for me she always wanted me to be in charge of my own life. I have supporters in my life not decision makers. We work together, and they respect my choices.



- I want people to know that I am capable.
- I just need help understanding things.
- People should help me decide, not decide for me. SDM lets me live the life I want. Thank you

How Much Do I Know?

1. Is it legal to practice SDM even if the bill hasn't passed?
2. Can a supporter be a paid staff member?
3. Can I change my supporters anytime?

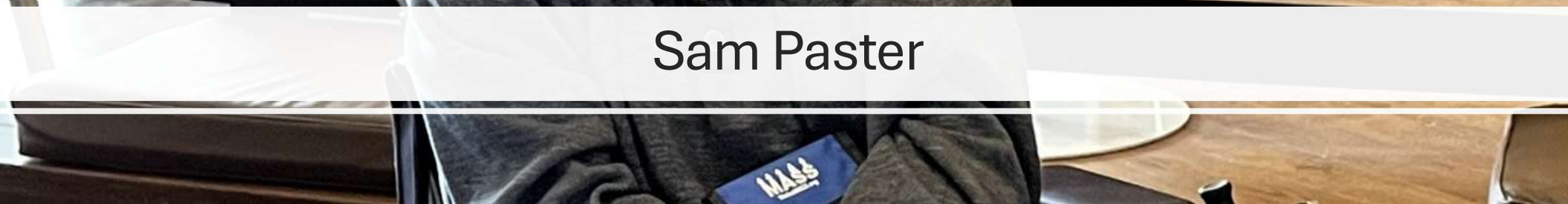


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- **Daysiree Perez-Batista**





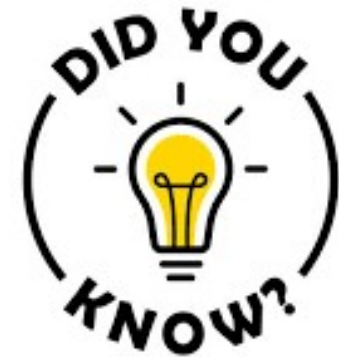
Sam Paster



Morgan Whitlatch

Facts about to Guardianship & Alternatives such as:

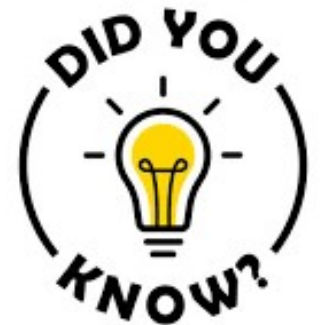
- A parent is not automatically the legal guardian when their child with disabilities turns eighteen years old.
- If an adult with a disability cannot make decisions independently, that does not mean they need a guardian.
- Guardianship does not guarantee safety.
- Guardianship is not needed to access an adult's medical or educational information, or to go to medical or educational planning meetings.



Morgan Whitlatch

Facts about to Guardianship & Alternatives such as:

- Guardians are not all powerful.
- A health care proxy is generally stronger than a guardianship when it comes to medical decisions.
- You do not need to be a person's guardian to be appointed their representative payee
- Supported Decision-Making is not only for people with certain kinds of disabilities
- You do not need to fill out a contract or agreement to use Supported Decision-Making



Tools & Resources

[Mass.gov/info-details/guardianship-alternatives-and-innovation-network-gain](https://www.mass.gov/info-details/guardianship-alternatives-and-innovation-network-gain)

**Thank you to all of our
panelists**

Question and Answer Period