Questions and Answers about Supported Decision-Making for Parents, Family Members, and Supporters in Massachusetts

1.) My loved one is turning 18, where should I start?

In Massachusetts, when people turn 18 years old, they become legal adults. This means the law says they get to now make their own decisions about their health care, education, finances, and other personal matters. Parents are no longer allowed to automatically make legal decisions for their adult child, even though they could typically do that all through their child's childhood. This is true even if the person has a disability, including mental, behavioral health, intellectual, and/or developmental disabilities.

This period can be an intimidating time for families, particularly when they do not know what all of their options are for supporting youth and young adults with disabilities in decision-making. Parents of youth with disabilities may be incorrectly told that the only way to remain involved in their child's adult life is to go to court and become a legal guardian. But that is not true. Getting guardianship is a serious step to take, and there are other options that may work better for the person and for the family without the need for guardianship. It is important to know all of those options, so that you and your loved one can choose the path that is right for your family. It is never too early or too late to learn about alternatives to guardianship. Some alternatives to guardianship in Massachusetts are: Supported Decision-Making, Shared Educational Decision-Making Authority, Health Care Proxy, Durable Power of Attorney, Delegation of Educational Decision-Making, and Representative Payee, among others.

You can learn more about these alternatives to guardianship in our "Key Words to Know in Massachusetts" document (available in <u>English</u> and <u>Spanish</u>) and our "Guardianship is Not the Only Option: Supporting Decisions in Adulthood" presentation (available in <u>English</u> and <u>Spanish</u>).

You can also check out our "Resources & Forms for Massachusetts Families" (available in <u>English</u> and <u>Spanish</u>), as well as our "Learn More About Supported Decision-Making" (available in <u>English</u> and <u>Spanish</u>) and our "Learn More About Guardianship" (available in <u>English</u> and <u>Spanish</u>) handouts.

2.) How do I know if Supported Decision-Making is right for my loved one?

Supported Decision-Making (SDM) is an option to consider for everyone, regardless of disability. A common myth about SDM is that it can only be used by people with certain kinds of disabilities. That is not true. A person's ability to use SDM is not determined solely by their diagnosis, IQ score, how they communicate, or their support needs. When considering whether guardianship is necessary, SDM should be among the list of possible alternatives discussed first for every person.

Even if a person has a court-appointed guardian, they can still benefit from using SDM principles in their lives. A guardian can and should promote a person's self-determination by including the person in decision-making and respecting and advocating for their preferences and choices.

For more information see our "Learn About Supported Decision-Making" handout (available in <u>English</u> and <u>Spanish</u>). You can also check out our "Getting Started with Supported Decision-Making in Massachusetts" guide (available in <u>English</u>).

3.) What types of decisions can a person use Supported Decision-Making for?

Supported Decision-Making (SDM) can be used for any decision – big or small – involving any area of a person's life, from decisions about health care, including mental health, finances, education, employment, voting, relationships, to anything in between. There is no one size fits all for SDM. People will use it differently depending on their wants and needs. For more information, see our "Guardianship is Not the Only Option: Supporting Decisions in Adulthood" presentation (available in English and Spanish) and our "Getting Started with Supported Decision-Making in Massachusetts" guide (available in English).

4.) How can I let others know that my loved one is using Supported Decision-Making?

There are a few ways that you and your loved one can let others know that they are using Supported Decision-Making (SDM).

First, a person should talk to their supporters, so everyone is clear about the kind of support that the person wants and needs to use SDM. You can also help your loved one introduce their supporters to the professionals in their lives, like doctors, attorneys, teachers, bank officials, case workers, and others. You can work together to explain to the professionals what SDM is and how your loved one makes decisions with the help of supporters.

Your loved one may also decide to make an SDM Agreement to share with the people and professionals in their lives. As we mention in our answers to Questions #6 and #7, an SDM Agreement is not required to use SDM, but some people find it helpful to make one. For more information about making an SDM Agreement, check out the answers to Question #7 and #9.

You can visit our "Getting Started with Supported Decision-Making in Massachusetts" guide (available in <u>English</u>) for more information about how to start using SDM.

5.) If my loved one is using Supported Decision-Making, do their supporters have access to their personal information?

No, not automatically. There are laws that prevent people like doctors or schools from sharing personal information about adults -- including adults with disabilities -- without their permission. These laws are there to protect people's private information. When your loved one is using SDM, they should consider giving permission for doctors or schools to share information with chosen supporter(s). To give that permission, your loved one would need to sign a "release-of-information" form.

You can learn more about release-of-information forms by visiting our "Getting Started with Supported Decision-Making in Massachusetts" guide (available in <u>English</u>). You can also check out our "Key Words to Know in Massachusetts" document (available in <u>English</u> and <u>Spanish</u>) to learn more.

6.) Can my loved one use Supported Decision-Making without making a Supported Decision-Making Agreement?

Yes. In Massachusetts people can use Supported Decision-Making (SDM) with or without an agreement. There is no requirement that a person create an SDM Agreement to use SDM. In fact, many people -- including people with and

without disabilities -- regularly use SDM without ever signing an SDM Agreement when they rely on people that they know and trust to help them make and communicate their own decisions. But sometimes having an agreement in writing can be useful, because professionals, like doctors, attorneys, school officials, and others may be more likely to honor a person's Supported Decision-Making arrangement if it is in writing. Agreements can also be helpful because they will lay out the specific role that the person wants each of their supporter(s) to play. Ultimately, the decision about whether or not to create an agreement is a personal one that your loved one can make.

For more information about thinking through this decision, check out our "Getting Started with Supported Decision-Making in Massachusetts" guide (available in <u>English</u>). Also, please see the answers to Questions #8 and #9, which include resources about using SDM and SDM Agreements.

7.) Can someone use Supported Decision-Making in Massachusetts even if the state legislature has not yet passed a law recognizing Supported Decision-Making?

Yes. Supported Decision-Making (SDM) is an existing legal option that people can use in Massachusetts. It is true that legislation formally recognizing SDM has not passed the Massachusetts legislature yet. However, SDM has been formally recognized in Massachusetts in other ways. Over a decade ago, Massachusetts had one of the first formal pilot projects that supported people with disabilities in using SDM in their lives. That first pilot resulted in the first court order to terminate a guardianship in favor of SDM in Massachusetts in 2015. There have been at least five additional SDM demonstration projects across the state since then. In addition, SDM can be seen as a reasonable accommodation for a person's disability under federal and state law. So, it is legal and can be used in Massachusetts and across state lines.

For more resources on using SDM, check out the answers to Questions #8 and 9.

8.) Are there resources that can help someone use Supported Decision-Making?

Yes. There are many resources that can help someone use Supported Decision-Making, these include:

- "Getting Started with Supported Decision-Making in Massachusetts" guide (available in English).
- "Omar's Journey with Supported Decision-Making" video (available in <u>English</u> and <u>Spanish</u>)
- "Keila & Omar's Journey with Supported Decision-Making" video (available in <u>English</u> and <u>Spanish</u>)

9.) Are there resources that can help someone create a Supported Decision-Making Agreement?

Yes. Check out these resources about making a Supported Decision-Making Agreement in Massachusetts:

- "Getting Started with Supported Decision-Making in Massachusetts" (available in <u>English</u>).
- "Sample SDM Agreement Forms and Instructions for Massachusetts Residents" (available in English and Spanish)

10.) If my loved one uses a Supported Decision-Making Agreement, should they have it notarized?

At this time, you are not required to get a Supported Decision-Making (SDM) Agreement notarized in Massachusetts, but it could be a useful step to make sure professionals accept and honor your loved one's agreement. To learn more about making an SDM Agreement and getting it notarized check out our "Getting Started with Supported Decision-Making in Massachusetts" guide (available in English).

11.) How does Supported Decision-Making work if my loved one has a mental health emergency?

Supported Decision-Making (SDM) can be an important tool if your loved one is having a mental health emergency. If your loved one has a mental health condition and uses SDM, they can think in advance about how they want their supporters to help them if an emergency happens. For example, they can talk to their supporters about what approaches or techniques help them feel safe and comfortable and what has not worked well for them in the past. Other questions to consider include: Where does your loved one want to receive mental health treatment when they need it? What treatments or medications do they want and

what do they not want? What services do they want to be connected to, like peer mentors and trauma-informed supports?

With the person's permission, supporters can also play an important role in communicating with mental health crisis workers, attorneys, hospital staff, law enforcement, and others in an emergency. For example, supporters may speak to these professionals about communication techniques or styles that might make your loved one feel more comfortable and safe, as well as what accommodations they may need. During these situations, supporters can also play a critical role in communicating with your loved one, so that they can more fully understand the decisions and situations they face. Because the relationship between a person and their supporter is built on trust, supporters can play a pivotal role in guiding and informing a person on their mental health journey.

You can check out our answer to Question #12 to learn more about SDM and health care proxies, which can be another important tool during a mental health emergency.

12.) How does a health care proxy work with Supported Decision-Making?

A health care proxy is a person your loved one can choose to make health care decisions for them if they become unable to make a decision for themselves. Health care proxies are recommended for all adults. A person should consider designating a health care proxy if they use Supported Decision-Making (SDM). Choosing a health care proxy allows a person to decide in advance who they would like as a health care decision-maker if there is an accident or emergency. Many people using SDM choose one of their supporters as their health care proxy. There is no conflict between using SDM and choosing a health care proxy. SDM is a model a person can use to help them make their own decisions every day, while a health care proxy is something that only gets used if there is an emergency that causes that person to be unable to make decisions for themselves, even with support.

Unlike some other states, Massachusetts does not distinguish between health care proxies and advance directives specifically for psychiatric care and treatment. However, some individuals write their health care proxies to specifically include their wishes and instruction for mental health care. If your loved one has a mental health condition, it might be useful for them to include

information about their mental health treatment in a health care proxy if an emergency occurs. For example, they may include what they want to happen during a mental health emergency, what hospital they prefer to go to, what medications they prefer and what medications they do not want used, and who they want to be contacted.

You can <u>read more about health care proxies in Massachusetts and get forms in</u> <u>English and Spanish at this website</u>. There is also more information about health care proxies in our "Getting Started with Supported Decision-Making in Massachusetts" guide (available in <u>English</u>).

13.) If I am my loved one's guardian, can I end the guardianship to use Supported Decision-Making?

Only a court can end guardianship. Once a guardian gets the guardianship order from the judge, the court will become part of the guardian's and the person's lives for as long as the person is under guardianship. Even if you do not want to have guardianship for your loved one anymore, it is a judge that gets to make the decision about ending or changing the guardianship. This can be done -- but it can take time and cost money -- and it is not guaranteed.

While a guardian alone cannot end the guardianship, a guardian can advocate for the guardianship to end. In that situation, you can help collect information about how your loved one can make decisions for themselves and help connect them with an attorney to represent them in restoring their legal rights. As we said in our answer to Question #2, a guardian can and should promote a person's self-determination by including them in decision-making and respecting and advocating for their preferences and choices. Often this is what many guardians strive to do.

To learn more, you can also check out our "Learn More About Guardianship" document (available in <u>English</u> and <u>Spanish</u>).