

Plain Language Report on the MASS Supported Decision-Making Task Force Regional Forums

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Summary

The Massachusetts Advocates Standing Strong (MASS) Supported Decision-Making (SDM) Task Force held 4 regional forums in fall 2018. At the forums, Task Force members asked self-advocates 22 questions. Task Force members took notes on what self-advocates said. Task Force members learned a lot from self-advocates and are sharing what they learned here:

- Self-advocates want new laws and policies to promote supported decision-making so that they can have more control over their decisions.
- Self-advocates want a new law or policy that focuses on giving training both for self-advocates on their decision-making rights and for other people on supported decision-making.
- Self-advocates are worried that written agreements will not be effective, especially without correct trainings.

Background

At its June 2017 board meeting, MASS decided to form a task force on SDM. With help from the Harvard Law School Project on Disability (HPOD), the Institute for Community Inclusion, and the Disability Law Center, the MASS SDM Task Force works to learn more about SDM and ways MASS might push for laws and policies that promote SDM.

On February 10, 2018, the MASS SDM Task Force organized a conference to understand the decision-making problems self-advocates deal with. The February 2018 meeting had 4 main takeaways:

1. self-advocates have issues getting others to respect their decisions, even if they don't have a guardian;
2. "supporters" often try to make decisions for self-advocates, even though the "supporters" believe themselves only to be helping;
3. for self-advocates that live in group homes, their representative can limit their choices to make financial decisions; and
4. self-advocates with guardians want their guardians to act as "supporters" instead.

To learn more, the MASS SDM Task Force organized four regional meetings across its 5 regions.

Method

The forums were led by Task Force members with support from MASS Regional Coordinators. Notes were taken by HPOD volunteers or MASS staff and allies.

Self-advocates who attended the forums answered the same 22 questions. The questions were asked in the style of a large group discussion. The note-takers took notes on what self-advocates said. The names of self-advocates who attended are not included in this report.

Below is what the MASS SDM Task Force learned from self-advocates at the forum meetings.

Summary of Findings

1. Different people said they had different amounts of control in different areas of their lives but wanted more control in decision-making areas.
2. Participants said they were most interested in laws and policies about trainings for self-advocates and people involved in decision-making.
3. People that were part of the forum felt differently about the supported decision-making agreements and how well they would help in decision-making freedom.

Detailed Findings

The responses were put into five categories:

- 1) Decisions that self-advocates do and do not control:
 - a. All participants said they had control of what they wear.
 - b. Participants had different answers on if they had control of where to work, who to marry or date, what to do for fun and when and how to get places.

- 2) What self-advocates don't want their supporters to:
 - a. Self-advocates do not want their opinions ignored.
 - b. Have supporters tell self-advocates they cannot do something without trying.
 - c. Have supporters sign healthcare forms for self-advocates.
 - d. Supporters try and make self-advocates live in group homes.

- 3) Trainings and resources for self-advocates:
 - a. Participants from all meetings felt that all self-advocates should be trained on what their rights are.
 - b. Participants liked the idea of having a law that would have other self-advocates help each other with supported decision-making like in ISP meetings.

4) Trainings for supporters, representative payees, and guardians:

- a. Most participants agreed their supporters needed more training and that training should be by self-advocates.

5) Written SDM agreements:

- a. Participants had mixed feelings about if SDM agreements would give them more control of their decisions.
- b. Participants wanted to see more information on what a SDM agreement would look like before deciding how they felt.
- c. Some participants felt the SDM agreements would make it seem like self-advocates could not make their own choices.

Discussion

Overall participants liked the idea of SDM because it can give them control of decisions they do not control right now. Participants also liked greater education and raising awareness for self-advocates and their decision-making rights. They also liked the idea of greater education for supporters and guardians. Participants approved of more training about self-

advocates' rights. This was an important point in the discussion. They also felt self-advocates should be a part of the training.

Conclusion

Participants were most worried about other people not liking SDM and making it difficult to work. Participants seemed to like laws and policies that made other people get training on SDM. These responses showed that the MASS SDM Task Force should explore how to make sure people who are supporters or self-advocates get training and understand self-advocates better.

Annex: Questions for Forum Participants

1. What decisions do you have A LOT of control over?
2. What decisions do you want MORE control over?
3. Do you believe you can make your own decisions, either with or without support?
4. What are the things that you don't want your supporters to do?
5. Do you want supporters talking to others about you without you being there at the same time?
6. How do you think you could stop supporters from doing the things you don't like?
7. What would be a good way to resolve disagreements that you might have with your supporters?
8. Do you want to get training on how to make specific kinds of decisions?
9. Do you want supporters to get training on how to help self-advocates make decisions?
10. What do you think trainings for either supporters or self-advocates should include, and who do you think would be the best trainers?
11. Do you want a law that requires training for self-advocates who have rep payees so they can learn about their rights?
12. Do you want a law that requires that ALL self-advocates with guardians receive training on their right to make decisions?

13. Do you want a law that requires rep payees who are staff or guardians to get training on supported decision-making as an alternative?
14. Do you want a law that will provide self-advocates, if needed, with trained supporters to advocate for them at important decision-making moments (like ISP meetings)?
15. Do you want a law that requires training on supported decision-making for transition-age students, so they can say what they want?
16. Do you want a law that gives self-advocates more freedom for deciding on how to budget and spend their money, because self-advocates have to get their budgets approved by others, who often limit self-advocates' control?
17. What would you want a written supported decision-making agreement (like a contract with your supporters) to say?
18. Do you think others might think you weren't able to make your own decisions anymore if you had a special written agreement (like a contract)?
19. Do you think others might try to use a written agreement (like a contract) to pressure you into making decisions you don't agree with?
20. Do you think making a written agreement (like a contract) with your supporters would make others respect your decisions more? Or less?

21. Do you think making a written agreement (like a contract) with your supporters would help to stop them from doing things you don't like?
22. Do you want to join the MASS SDM Task Force?