

MEMORANDUM

TO: MASS Supported Decision-Making (SDM) Task Force
FROM: Hezzy Smith, Harvard Law School Project on Disability (HPOD)
DATE: December 8, 2018 (*updated February 6, 2019*)
RE: Report on Regional Forums (October-November 2018)

Executive Summary

The responses of participants to a list of 22 questions presented during four regional forums organized by the MASS SDM Task Force in late October and early November 2018 indicate the following three points:

- MASS members want new laws and/or policies to promote supported decision-making so that they can have more control over their decisions.
- MASS members want a new law or policy that focuses on providing trainings both for self-advocates on their decision-making rights and also for others on supported decision-making.
- MASS members have concerns that written SDM agreements will not be effective, especially without trainings for key stakeholder groups.

Introduction

At its June 2017 executive board meeting, MASS decided to form a task force on supported decision-making (SDM). With the support of HPOD, the Institute for Community Inclusion (ICI), and the Disability Law Center (DLC), the MASS SDM Task Force aims to explore SDM and avenues by which MASS might advocate for laws and policies that promote SDM.

On February 10, 2018, the MASS SDM Task Force organized a statewide consultation to understand the decision-making barriers faced by self-advocates. The February 2018 consultation yielded four key takeaways:

- self-advocates often have difficulty getting others to respect their decisions, even if they don't have a guardian;
- "supporters" often try to make decisions for self-advocates, even though the "supporters" believe themselves only to be helping;
- especially for self-advocates that live in group homes, their representative payees can limit their opportunities to make financial decisions; and

- self-advocates with guardians want their guardians to act as “supporters” instead.

To collect information that could inform future law- or policy-making efforts to address these barriers to decision-making, and also to make more MASS members aware of SDM, the MASS SDM Task Force organized four regional forums across its 5 regions on October 27, November 3, and November 10, 2018.

Methodology

The discussions at each forum were facilitated by Task Force members with the assistance of MASS Regional Coordinators and notes were taken by HPOD volunteers or MASS staff and allies, as listed below.

<i>Region(s):</i>	Southeast	Central & West	Northeast	Metro
<i>Date:</i>	Oct. 27 th	Oct. 27 th	Nov. 3 rd	Nov. 10 th
<i>No. of Forum Participants:</i>	7	10	9	8

All forum participants responded to the same list of 22 questions developed by the MASS SDM Task Force members (see Annex A). Facilitators used illustrated PowerPoint slides and printed handouts developed by the Task Force (see Annex B) to explain:

- the purpose of the forum,
- what supported decision-making means,
- what the Task Force had done to date, and
- the questions put to the forum participants.

At each forum, which lasted approximately 3 hours, facilitators presented participants with the same questions in the same order. Many questions were elaborated upon, rephrased for clarity, and illustrated through examples. Facilitators sought to foster semi-structured discussions, rather than record systematically each participant’s response to each question. In the semi-structured discussions flowing from the facilitators’ prompts, forum participants’ responses to certain questions bled into discussions about subsequent questions. Note-takers took notes using a common recording format.

This report, discussed with and revised by the MASS SDM Task Force at its December 2018 monthly coordination meeting, presents findings from these regional forums.

Summary of Findings

- 1) Overall, forum participants appeared to report having different levels of control over different areas of their lives and wanted more control over certain decision-making areas.
 - Participants reported greatest amount of control over deciding what to wear, and the least amount of control over financial decisions.
 - Participants living in group homes generally appeared to experience less control over their decisions than those living in other settings.
 - Participants generally expressed frustration that they were not permitted sufficient opportunities to make their own decisions, that others decided the kinds of support they received, and that others frequently discussed them outside of their presence and without their permission.
- 2) Forum participants appeared to be most interested in laws and policies that would provide trainings both to self-advocates and also to key stakeholders that affect their decision-making.
 - Participants generally recognized the usefulness of providing self-advocates with training on their decision-making rights, but also specifically for self-advocates who have representative payees and guardians so that they can know their rights.
 - Fewer participants expressed interest in receiving training on how to make decisions.
 - Participants expressed the most interest in requiring that supporters, representative payees, and guardians receive training on supported decision-making as a way to help self-advocates get more respect from those who often get in the way of their decisions.
- 3) Forum participants' views of whether written SDM agreements would further the goal of increasing decision-making autonomy were mixed.
 - Some participants were more skeptical than others about whether written SDM agreements would make others respect self-advocates' decisions more or less.
 - Many participants were concerned that agreements could be used against them by agencies or misinterpreted by third parties, such as doctors, as permission to deal directly with supporters.
 - Participants in all forums stressed that any agreements should be:
 - highly personalized to ensure self-advocates' voices are heard,
 - written very carefully in order to give self-advocates greater control over decisions in the areas where they struggled to do so, and
 - explained very clearly to self-advocates so that they understand what the agreements can and cannot be used to do.

Detailed Findings

Forum participants' responses are presented below in summary format. Despite using a common note-taking template, there was variation in the quality and depth of the notes from each forum, reflecting variation both in the kinds of responses elicited from different groups of participants as well as in the note-takers' note-taking methods. Therefore, the summaries below reflect the Task Force's intent to identify broadly areas of consensus and areas of divergence of opinion with regard to legislative and policy solutions to decision-making barriers.

Forum participants' identities are kept anonymous throughout, although the forums where specific issues were raised or emphasized are noted using the following abbreviations, in order to aid reference to note-takers' notes: Southeast (SE), Central & West (CW), Northeast (NE), and Metro (M). The summaries of participants' responses to the facilitators' discussion questions are grouped into five topic areas, following the general order in which the questions were presented:

- 1) decisions that self-advocates do and do not control;
- 2) what self-advocates don't want their supporters to do;
- 3) trainings and resources for self-advocates;
- 4) trainings for supporters, representative payees, and guardians; and
- 5) written SDM agreements.

Last, the summaries below have some limitations. Because of the semi-structured format of forum discussions, some participants provided more responses than others. Also, some participants' responses may have been affected by the presence of support workers who accompanied them. Nevertheless, the importance of self-advocate facilitators in eliciting participants' responses can hardly be overstated. In the forums, many self-advocates spoke up forcefully and passionately when prompted by facilitators.

1. Decisions That Self-Advocates Do and Do Not Control¹

The only area where self-advocates uniformly reported having control of their decisions was what to wear. Some self-advocates reported having control of decisions in the following areas, while others reported not having enough control:

- Where to work (yes - CW, M; no – NE, M, SE)
- Who to marry or to date (yes – CW; no - CW)
- What to do for fun (yes - NE, M, SE; no – NE, SE)
- How and when to get places (yes – M; no – CW, SE)

¹ This section summarizes responses to questions 1-3 (see Annex A).

- What to eat (yes – NE, SE; no – M)

Last, self-advocates most frequently reported not having enough control over the following decisions:

- How to spend money (CW, M, SE)
- Where to live (CW, NE, SE)
- Staffing hours and service-related decisions (CW, NE, M, SE)

One NE participant reported feeling like an “octopus” being pulled in eight different directions by his “supporters,” who he believes are “running my life.” He expressed frustration that even when he tells others that he is his own guardian and his own advocate, he feels that “there are just too many people making decisions for me.” He wanted “more tools to keep my staffers in check.” A CW participant frankly stated, “Sometimes people who aren’t their own guardian don’t get listened to.”

Several M participants living in a group home expressed deep frustration with their grocery shopping. They reported not being allowed to decide on which day they go grocery shopping and that the staff decided based on what was convenient for them and not what the M participants preferred. Another M participant reported the same lack of control over her schedule with regard to when she goes to the gym to exercise. Another M participant understood why they had to plan their group home meals in advance but was frustrated that they could never deviate from them, even though people outside group homes who are on diets can decide to break their diet whenever they choose. A NE participant reported similar frustrations regarding food shopping. He said that he had to sneak out of his group home when his staff wasn’t looking.

Overall, the participants who lived in group homes reported less control over decisions than the participants who lived in other settings. They were also more likely to report that paid staff interfered with their decision-making than others who lived in other settings. For example, a NE participant reported having more control over his decisions before he moved into a group home. More poignantly, a SE participant expressed frustration that although she needs help with dressing and showering, she definitely can live in a more independent setting than a group home, where she cannot choose her roommates or staff. Her frustration with her current living situation and her restricted decision-making is that she believes her personal care assistant’s (PCA) negligence was the reason why she was placed in a group home. SE participants felt that persons using wheelchairs generally had less control over their decisions than self-advocates who do not use wheelchairs. One SE participant was especially frustrated to be the only one of her roommates who communicated verbally.

Self-advocates generally did believe they could make their own decisions, either with or without support. CW participants generally agreed that they needed more help with financial decisions than in other areas, although they still believed that they were able to make their own decisions if they had the right support in place to do so. A NE participant expressed deep frustration that she believed she had become homeless for a time, not because she was incapable of making housing decisions, but simply because she wasn't given adequate information by agencies whose job it is to help connect people to housing options. A M participant expressed frustration that he wasn't allowed to go shopping and be trusted with handling money, even though he believes he can do it.

At the same time, a NE participant who had been taken advantage of financially by a friend wished he had had access to better supports at that time. Although he doesn't want to be taken advantage of again, he doesn't want to have to sacrifice any of his decision-making freedom in order to get those supports.

2. What Self-Advocates Don't Want Their Supporters to Do²

Forum participants generally do not want their supporters to do the following:

- Ignore their opinions or try to talk them out of things or change their minds (CW, NE, M, SE)
- Meddle with their living situations, like trying to push them into group homes or keep them from moving out (CW, NE, SE)
- Sign healthcare or other forms for them or speaking to healthcare professionals instead of to them (NE, M, SE)
- Spend time on their phones and devices (CW, M)
- Tell them they're not capable of doing things without giving them the opportunity to try (CW, M)

Forum participants also bristled at others determining what kinds of supports they needed. One M participant expressed frustration with her case manager, who "says she doesn't think I can do it, but how do you know unless you try? That's how I look at it." Another M participant stated that she doesn't like not being able to decide when she needs support and when she doesn't. She stated, "I don't have people go with me to foot doctors. But psychiatrists? Yes." A CW participant was frustrated when his staff insisted on helping him to get groceries even though he tells them he doesn't need groceries because his wife had already gotten him groceries: "I would prefer to do something that I actually want to do" when his staff works with him on Wednesdays. A NE participant expressed frustration that her "supporters" frequently

² This section summarizes responses to questions 4 through 7 (see Annex A).

tried to talk her out of how to spend her money, even though they believed that they were helping her instead of interfering with her decisions.

Specifically, forum participants do not want their supporters talking about themselves to others without being present. One NE participant stated that “it feels like [her supporters] get together behind my back and talk about me.” Another NE participant took issue with the fact that his provider agency routinely meets to discuss people who aren’t in the room. A CW participant stated that her doctors and staff “always” talked about her behind her back. She described a time when a doctor gave information about test results over the phone to her staff even though she was her own guardian and didn’t consent to sharing that information. A SE participant pointed out that if others talk about self-advocates outside of self-advocates’ presence, “If they have something to say, they should say it in front of you. How do we know what they’re saying is true?”

A M participant described feeling “terrible” when she is upstairs in her bedroom and hears staff talking about her. Another M participant reported that while at the doctor’s office: “There are certain things I do want to be alone at the doctor for . . . but [my case manager] is not letting me.” Specifically, she felt that she should be able to fill out medical forms necessary to renew her enrollment with the Ride, which her staff routinely denies her the opportunity to do. On the other hand, one CW participant stated that s/he didn’t have a problem with supporters speaking to others, for example, with looking for housing or jobs, because in those cases it helps to get the word out and s/he’s not worried about privacy.

To prevent supporters’ undesirable behaviors, forum participants emphasized the importance of training for supporters (see Section 4 below). Some self-advocates had specific strategies for doing so. Another CW participant wanted supporters to talk to others “only if I have given a consent form.” A M participant was very specific that when she met with a counselor that she wanted to start and end her sessions alone, while she was open to having staff be present in the middle of the sessions. Another M participant described very specifically how her sister tries to micromanage how she spends the money her sister gives her; the M participant’s workaround is simply to sneak purchases she doesn’t think her sister would approve of. At the same time, a SE participant observed that although staff receives conflict resolution training, “it doesn’t seem like they use it.”

In order to resolve disagreements that arise with supporters, some CW participants suggested having trained third-party mediators to review or intervene. With such a system, however, they emphasized that the mediators would have to be from outside DDS and not be associated with agencies to ensure that they were impartial. They complained that DDS human rights officers often did not investigate self-advocates’ complaints seriously.

3. Trainings and Resources for Self-Advocates³

Some forum participants expressed interest in receiving training on how to make some kinds of decisions, while others thought they didn't need training to make decisions so much as the opportunities to practice making decisions so that they could learn from mistakes and become better as they go. That said, one NE participant recalled a positive experience she had received several years ago on "choice and control."

But participants from all the forums did strongly believe that all self-advocates with representative payees should receive training on what their representative payees can and cannot do and that this training should be required by law. Similarly, self-advocates strongly believed that self-advocates with guardians should receive training on their decision-making rights and that such trainings should be required by law.

Forum participants also felt that transition-age youth receiving special education services should by law receive training on supported decision-making as part of their education. They felt that this would be an effective strategy for preventing unnecessary guardianships. Several NE and M participants wished they had received this kind of training on "how to be my own guardian" (M) before they left school. However, SE participants did not believe that a law requiring that transition-age students be exposed to SDM may strictly be necessary, but that SDM should in practice become the standard in transition planning processes.

Forum participants generally felt that supported decision-making shouldn't be contingent on access to natural supporters. Often, natural supporters, while helpful in certain areas, could overstep their roles in others. Therefore, many self-advocates expressed a preference for a law that would enable peers who have been trained in supported decision-making to assist them during important decision-making moments, such as ISP meetings (SE, et al.). At the same time, one M participant described how her service coordinator was very effective at helping her to manage meetings and prevents her family members from "walking all over me."

Forum participants had fewer concerns about having greater freedom on managing participant-directed program (PDP) funds. This seemed at least partially due to the lack of experience many of the CW and M forum participants had with participant-directed funds: many of them received traditional services. Even so, the NE forum participants had more responses to this question than the others. A NE participant noted that even with the Real Lives Act, she struggles to control her PDP budget. She noted that even though the law has good provisions and the staff are trained on it, often the staff aren't incentivized to follow it. Another NE participant believed that there should be fines or repercussions for interfering with self-

³ This section summarizes responses to questions 8, 11, 12, and 14 through 16 (see Annex A).

advocates' decision-making, because staff would continue to not follow the law if there weren't consequences for not following it. Another NE participant who shared that he had participated in the drafting of the Real Lives Act stated that he had been disappointed with it because even though PDP funds go directly to the bank, which his mother has greater access to than himself, allowing her to dictate how he spends it. He would prefer to receive physical checks rather than direct deposits because he feels that would give him greater control.

4. Trainings for Supporters, Representative Payees, and Guardians⁴

Forum participants demonstrated the greatest consensus on questions addressing whether others who affect self-advocates' decision-making should receive training on supported decision-making. Forum participants expressed greater interest in getting their supporters training on how to support them to make their own decisions than in getting support to become better at making decisions. One M participant replied sarcastically that her "supporters" would "need a lot more than training."

Forum participants also seemed to have a consensus that such trainings, regardless of their content, should be given by self-advocates. Some CW and M participants suggested that non-self-advocates should also be involved, especially to train supporters, because they anticipated that self-advocate trainers, if alone, would face credibility concerns. They generally strongly believed that service providers should not be trusted to conduct these trainings.

Across the forums, the participants strongly believed that both representative payees and guardians should be required by law to receive training on supported decision-making.

5. Written SDM Agreements⁵

Forum participants had mixed opinions on whether written SDM agreements would in practice enable them to make more of their own decisions with support. Some participants expressed concern that written SDM agreements might expose them to the possibility that others would view the agreements as evidence of their inability to make decisions on their own. Many participants seemed to want more information about what an agreement would look like in order to have a more informed opinion.

Some CW participants thought it would be useful to distinguish between the things they would like support for and the things they don't need support for. Some thought an agreement could be useful if it functioned like a job description for supporters. But they cautioned that the agreement should both be highly personalized and also involve a lot of discussions with

⁴ This section summarizes responses to questions 9, 10, and 13 (see Annex A).

⁵ This section summarizes responses to questions 17 through 21 (see Annex A).

supporters, because they didn't believe that a piece of paper would change things all that much. (Similarly, an M participant said that an effective agreement had to be more than a series of boxes that a self-advocate checks off.) They were concerned that the agreement might give doctors, for example, the impression that they could talk directly with supporters and bypass self-advocates, at the same time that many CW participants admitted that's how many doctors operate now, even without the agreements. They were especially distrustful of how agencies would use written SDM agreements, voicing their concern that even if the agreement barred them from using the agreement against a self-advocate, they would disregard it at their convenience. The CW participants were equally divided on whether a written agreement would make others respect self-advocates' decisions more or less.

Some NE participants thought the agreement could be useful, but that it would have to be a lot simpler than most contracts. It should also have images or labels to help explain to self-advocates what each part means. While NE participants thought that agreements might make others believe that self-advocates couldn't make their own decisions, one NE participant voiced his opinion that it was a risk worth taking if the agreements could help hold supporters accountable. At least one NE participant strongly believed that a written agreement wouldn't change others' attitudes about what self-advocates can and cannot decide. Another NE participant believed that unless money were involved, the contract wouldn't make a difference. She feels like she can hold her paid staff accountable for the kinds of support they provide precisely because she can fire them if she doesn't like what they do. She doubted that simply removing a supporter from a written agreement would provide a similarly powerful incentive. The NE facilitator worried that a written agreement might become too restrictive. For example, if a self-advocate wanted a kind of support not stated in the agreement, then a supporter might not want to provide that support until they had added it to the agreement, which could possibly make accessing decision-making supports more cumbersome.

Most M participants believed they didn't need a written agreement in order to get the support they needed in certain areas to make decisions. However, one M participant believed that others would be impressed by a written agreement and consider her more independent as a result. Another M participant believed that his mother would respect his decisions more if she had signed an agreement stating that she would do that, although it would have to be written "in a certain way" that made his right to make his own decisions very clear.

SE participants shared other forum participants' beliefs that while a law recognizing SDM agreements might have adverse consequences, there should be a law at least requiring that SDM agreements be considered as a less restrictive alternative to guardianship.

Discussion

Forum participants appeared to embrace the concept of supported decision-making insofar as it can give them more control over decisions that they currently do not have as much control over as they would like. They clearly endorsed the need for greater education and awareness-raising among self-advocates about their decision-making rights. They similarly endorsed the need for greater education of supporters, representative payees, and guardians about supported decision-making to further their goal of giving self-advocates more control over their decisions. Forum participants also expressed some interest in receiving greater supports to make their own decisions, whether through trainings on how to better make financial decisions or through access to trained peer supporters at ISP and IEP meetings.

However, forum participants' views about the role of written agreements as effective tools for enabling supported decision-making appear to be mixed. The differing views about written agreements may reflect their lack of familiarity with the contents of agreements and also with how agreements would work in practice. To the extent to which agreements are used to enable supported decision-making, based on participants' concerns, agreements should be designed to ensure that they:

- enable self-advocates to exercise greater control over decisions they want more control over,
- empower self-advocates to regulate the extent to which supporters have access to and share their personal information with others,
- do not confuse third parties or supporters themselves about what supporters are permitted to do and not to do, and
- do not expose self-advocates to the risk that supporters or third parties might use the agreements to their own advantage.

By contrast to the written agreements, forum participants' apparent consensus on requiring training on supported decision-making suggests that this may be self-advocates' priority for any law- or policy-making effort. Participants emphasized the need for self-advocates to receive trainings about their rights, especially for self-advocates who have representative payees and guardians. Participants especially underscored the need for others to be trained on supported decision-making so that they have more respect for self-advocates' right to make decisions. While the contents and delivery method of such trainings were not discussed in detail, forum participants appeared to believe that the more that others knew about supported decision-making, the more likely it would be that self-advocates would have their decisions respected. They did suggest that self-advocates should be significantly involved in designing and delivering

the training, although for practical reasons, they believed that non-self-advocates of their choosing should be involved so that training recipients would give the trainings more weight.

Conclusion

Forum participants seemed to be most concerned about others' attitudes creating barriers to their decision-making, and they seemed to express the greatest enthusiasm for laws and policies requiring others to receive training on supported decision-making. Thus, in order to address the priority areas implicit in the forum participants' responses, the MASS SDM Task Force should consider exploring how to ensure that key stakeholder groups receive training on supported decision-making and that self-advocates receive training on their decision-making rights before exploring how supported decision-making should be reflected in written SDM agreements.

Indeed, requiring extensive training among key stakeholder groups might be the most effective way to ensure that written SDM agreements, whatever form they may take, have their intended effect. By contrast, introducing written agreements without requiring meaningful trainings for those affected by those agreements may repeat the errors of previous well-intentioned law- and policy-making efforts, such as the failure to provide community-based alternatives to institutional living facilities. The MASS SDM Task Force should remain vigilant about the concerns that many forum participants expressed about the possible negative consequences of written SDM agreements.

Annex A – Fall 2018 Regional Forums List of Questions

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?

Annex B – Fall 2018 Regional Forum PowerPoint Slides

GROUND RULES

- This meeting is for self-advocates!
 - Others are asked to sit to the side and let self-advocates participate first.
 - (If you're helping someone speak up that's okay!)
- All cell phones should be on vibrate or silent
- One person should speak at a time
- Please raise your hand before speaking!
- Summaries of your responses will be recorded by note-takers (but without your names)

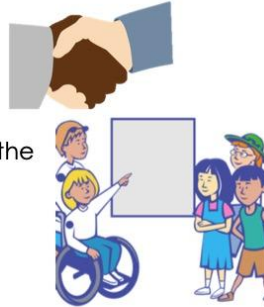
WHAT IS SUPPORTED DECISION-MAKING?

- "Supported Decision-Making" gives self-advocates the help they need to make choices about their own lives.
- These choices could be about where to live, what to do during the day, how to spend money, or when to see a doctor.
- Everyone needs supports to make decisions. Some self-advocates may need more or less or different kinds of supports.



WHAT IS SUPPORTED DECISION-MAKING?

- With supported decision-making, the self-advocate chooses the person(s) that will help with making decisions. They are called "supporters."
- The supporter gives advice, but the self-advocate makes the final decision.
- A good supporter respects the wishes of the self-advocate.
- A good supporter listens and suggests ways to make the self-advocate's wishes happen.



EXAMPLE OF A GOOD SUPPORTER

- For example, imagine that you want to find a place to live, on your own or independently.
- You don't know how to make decisions about location and how much you can afford.
- You ask your sister/brother for help.
- Your sister/brother comes to your house and asks you questions about what kind of apartment you want.



EXAMPLE OF A GOOD SUPPORTER

- Your supporter listens and talks to you about:
 - How much money you get each month?
 - How much you spend on other things like food and clothes?
 - How much money you can afford to pay in rent each month?
- Your supporter helps you look at apartments in the area you want to live in.
- Your supporter helps you understand that an apartment that you may not be able to afford an apartment that has everything you want.



EXAMPLE OF A GOOD SUPPORTER

- Your supporter helps you figure out which of the things you want in an apartment that are most important to you.
- Your supporter helps you to visit apartments.
- You then decide which apartment you want and sign a lease.
- At the end of this process you have received support, but you still **made all of your own decisions!**

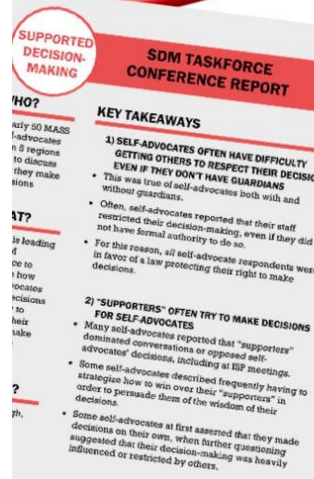


ABOUT THE MASS SDM TASK FORCE



- In June 2017, MASS decided to form a group to learn more about supported decision-making.
- In the Fall of 2017, MASS decided to prepare a statewide forum to learn about the challenges that self-advocates face when making decisions every day.
- The statewide forum was held on February 10, 2018.

ABOUT THE MASS SDM TASK FORCE CONFERENCE REPORT



- February 2018, 50+ self-advocates came to share their many different experiences
- MASS took notes of what self-advocates said and made a summary of its key takeaways
- MASS wants to make sure self-advocates' voices are heard statewide



ABOUT THE MASS SDM TASK FORCE

The 4 key takeaways from the statewide forum:

1. Self-advocates often have difficulty getting others to respect their decisions, even if they don't have any guardian
2. "Supporters" often try to make decisions for self-advocates
3. Self-advocates that live in group homes, their rep payees can restrict access to financial decision-making
4. Self-advocates with guardians want their guardians to act as "supporters" instead



ABOUT THE MASS SDM TASK FORCE

- MASS has been using all key takeaways to advocate for self-advocates
- Now, MASS wants to know what laws and policies self-advocates think can help them face challenges to making decisions
- It's time to speak up! Our motto, " Nothing about us without us!" or nothing about you without you!
- MASS has made these following questions to learn what ideas for future laws or policies self-advocates think will be the most useful



QUESTIONS FOR SELF- ADVOCATES

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?



QUESTIONS FOR SELF-ADVOCATES

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?



QUESTIONS FOR SELF-ADVOCATES

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?



QUESTIONS FOR SELF-ADVOCATES

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?



QUESTIONS FOR SELF-ADVOCATES

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?



QUESTIONS FOR SELF-ADVOCATES

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?



QUESTIONS FOR SELF-ADVOCATES

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?