

# SUPPORTED DECISION- MAKING

# SDM TASKFORCE CONFERENCE REPORT

## WHO?

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Nearly 50 MASS self-advocates from 5 regions met to discuss how they make decisions

## WHAT?

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MASS is leading an SDM taskforce to explore how self-advocates make decisions and how to protect their right to make their own decisions

## WHERE?

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Marlborough, MA

## WHEN?

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February 10, 2018

## KEY TAKEAWAYS

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### 1) SELF-ADVOCATES OFTEN HAVE DIFFICULTY GETTING OTHERS TO RESPECT THEIR DECISIONS, EVEN IF THEY DON'T HAVE GUARDIANS

- This was true of self-advocates both with and without guardians.
- Often, self-advocates reported that their staff restricted their decision-making, even if they did not have formal authority to do so.
- For this reason, *all* self-advocate respondents were in favor of a law protecting their right to make decisions.

### 2) "SUPPORTERS" OFTEN TRY TO MAKE DECISIONS FOR SELF-ADVOCATES

- Many self-advocates reported that "supporters" dominated conversations or opposed self-advocates' decisions, including at ISP meetings.
- Some self-advocates described frequently having to strategize how to win over their "supporters" in order to persuade them of the wisdom of their decisions.
- Some self-advocates at first asserted that they made decisions on their own, when further questioning suggested that their decision-making was heavily influenced or restricted by others.

## **WHY?**

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MASS SDM taskforce members wanted to know what self-advocates want in a new law that promotes supported decision-making

## **HOW?**

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MASS SDM taskforce members made a list of questions about how self-advocates make decisions, put them to the attendees, and wrote down their responses

### **3) FOR SELF-ADVOCATES LIVING IN GROUP HOMES, REPRESENTATIVE PAYEES CAN RESTRICT ACCESS TO FINANCIAL DECISION-MAKING**

- Many self-advocates reported that staff would often delay in taking them to the bank at their request.
- Others stated that representative payees' priorities for using their money and benefits often diverged from their own, and they didn't have final say.
- Others did not know whether they had representative payees, some asserting they did not have one when in fact their group home received and handled monthly benefits payments for them.

### **4) SELF-ADVOCATES WITH GUARDIANS WANT THEIR GUARDIANS TO ACT AS "SUPPORTERS" INSTEAD**

- Even for hard decisions, self-advocates generally expressed a preference to get support to make their own decisions instead of having others decide for them.
- Many self-advocates were reluctant to criticize their guardians' influence on their decision-making, even if they later stated that they wished that they had more opportunities to make their own decisions.
- For some self-advocates, it was challenging to differentiate between "not having a guardian" and "not having someone to support them to make decisions" instead, suggesting this concept is new to them.