



SAMUEL CENTRE
FOR SOCIAL
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Harvard Law School
Project on Disability

Supported Decision-Making:

A self-advocate's ten commandments for community
members

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Samuel Centre for Social Connectedness

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BACKGROUND

Chester Finn is a 2021 Social Connectedness Fellow, who has spent his 2021 Fellowship working with the Harvard Law School Project on Disability (HPOD) and Massachusetts Self-Advocates Standing Strong's (MASS) Supported Decision-Making (SDM) Task Force to understand self-advocates' priorities for future State legislation on SDM. As noted on the MASS website, "Supported Decision Making (SDM) is a new alternative to guardianship. It would allow self-advocates to assign supporters to help them with specific topics. Unlike guardianship, Supported Decision Making does not involve a judge."¹ Broadly speaking, Supported Decision-Making is one means through which individuals living with disabilities can reclaim their own independence, by making their own decisions on the issues that will impact their lives.² Throughout his Fellowship, Chester has worked alongside HPOD and MASS to conduct interviews with MASS advocates, the results of which will continue to support the broader implementation of a Supported Decision-Making framework for self-advocates within an American context, particularly within the state of Massachusetts.

Chester has been a strong advocate for people with developmental disabilities for more than 20 years. He currently works as a Special Assistant to the Commissioner at the Office of Persons With Developmental Disabilities for the New York State.

Chester grew up in western New York, attending school in Lockport and earning his

¹ Massachusetts Self-Advocates Standing Strong (MASS), "Supported Decision Making," accessed August 31, 2021. <https://www.wearemass.org/supported-decision-making>.

² Bill Alford, Anne Fracht, Marie Hennessy, and Hezzy Smith, "How to Strengthen the Americans with Disabilities Act after 30 Years: Promoting Supported Decision-Making for Persons with Intellectual and Developmental Disabilities", *Harvard Law Review Blog* (August 7, 2021). <https://blog.harvardlawreview.org/how-to-strengthen-the-americans-with-disabilities-act-after-30-years-promoting-supported-decision-making-for-persons-with-intellectual-and-developmental-disabilities/>.

associate degree from Genessee Community College in Batavia. He is passionate about upholding the rights of people with disabilities everywhere. His goals are to leave things in a better place and be able to teach and mentor young people to be advocates for themselves and others.

INSIGHTS INTO SELF-ADVOCACY

Supported decision-making is designed so that an individual will be able to take control of their life and make their own decisions. They can have people to support them rather than have other people or guardians making these important decisions for them. This is supported both throughout the country and internationally. People can choose a designated person or family member to speak on their behalf, but they are ultimately making the decision themselves. This is necessary because many states encourage families and agencies to become guardians over a person at an early age. People's lives are sure to change over time and the things they need in their lives change with them. This does not mean that a person cannot make decisions, but that they need support to make what they want happen. We have it in the name "Supported Decision-Making," because it gives the person freedom and independence. We have support for this in our Constitution and CRPD internationally to help people with their rights along with the representatives from the United Nations. This is why we should honor the rights of people to choose the direction their life takes. Having a legal document with these rights detailed in it, gives the person the protection they need. Supported Decision-Making is freedom.

The MASS SDM task force is a good way for people with disabilities to advocate and speak up for their rights. The state of Massachusetts and provider agencies were talking about Supported Decision Making and what that would mean both for individuals and the people involved in their lives. The Harvard Law School Project on Disability gave a presentation to MASS on Supported Decision-Making. We all know and live by the motto “Nothing About Us Without Us.” This is a phrase that came from South Africa. It means if someone wants to make any decisions about me, I need to be at that table.

MASS advocates designed a task force led by self-advocates, people with intellectual and developmental disabilities, and people who support them. I thought this was an excellent idea, because the advocates work with people across the state spreading freedom and independence. The task force also came up with a tool to help individuals with Supported Decision-Making. This is groundbreaking, because it was based on what was happening in people’s everyday lives and the support that they need and want. I know of nowhere else in the country where you had Supported Decision-Making led by self-advocates. I was asked by Hezzy Smith, the Director of Advocacy Initiatives at HPOD, and Professor Stein, the co-founder and Executive Director of HPOD, if I wanted to apply for a fellowship from the Samuel Centre for Social Connectedness. I said yes, and filled out the application, had an interview, and was accepted. One of the things that were great about this is that we had Fellows from around the world and we were able to learn from their experiences, and the partners they worked with. An important point is that we got to learn from each other.

What I learned from the task force was that the task force had learned from people living in different places and the different situations they were in. A lot of people came from group homes or were in institutions and sometimes they didn't have the power or authority to make their own decisions. For the task force, it was important to make sure that people could have control over the decisions they had to make about their lives. They also had people that could support them, whether it was staff or someone they knew. For the task force, they put a lot of thought into coming up with a tool that could work for everyone, and that had power and teeth. What I mean by "teeth" is that it wasn't just a piece of paper; it was a legal document. The task force did an excellent job when they interviewed people about their lives and what they could change. One of the things I observed is that the task force came up with the ideas and questions to respect the needs of the individuals and figure out the things they need to make Supported Decision-Making work for them. The task force should be commended for this. I came up with some tips as we presented the information to the task force. I call these tips the 10 Commandments. The task force liked that idea. The ten tips I came up with are:

1. Give people time to think about what a question means to them and say things in their own words.
2. Give people the chance to ask about something that they don't understand before you explain it to them.

3. Make sure all facilitators know their roles and give each other time to do their parts.
4. Be prepared to do role play to help explain things on the agreement form.
5. Keep track of time and don't spend too much time on one thing.
6. Focus on support for **deciding** things, not for doing things.
7. Spend more time talking about who could be good supporters and what supporters look like.
8. Make sure people talk about the support that they **want** in the future, not just the support that they are getting now.
9. Talk about how the person will use the agreement in their lives and try to educate them about other ways they could use it, too.
10. Share examples from your own life about the hard decisions you made with support.

We talked about in the task force what MASS could do next, and we are thinking about creating another tool to help with that, but I think that the task force and the MASS advocates will be on the same page, and I was asked to be a special advisor to

help in this goal.

One of the thoughts about self-advocates doing Supported Decision-Making across the country or worldwide is that the effort should be led by self-advocates because they are the ones that are living the lives and the ones that want to change where they live and what their situations are. In order for Supported Decision-Making to work, professionals have to listen to what people are talking about and figure out how to support them and the things they want to do for their lives and become more independent. Professionals need to help people accomplish their goals and not be dismissive of them. Like I said before, it's important for self-advocacy organizations to take the lead and push Supported Decision-Making because they can have allies from family members. There are family members that are guardians that want to support individuals to take more control of their lives. There are individuals that need more support but it's important to make sure you cover all the areas they need. That means listening to each other. When one group takes control over another group you create isolation and people are cut off. You want to give people an opportunity and that's what Supported Decision-Making will do. It will give people independence, freedom, and the support to create a life of their own.

Self-advocates need to take the lead at these meetings, and not just be present. They need to take an active role. Self-advocates need to fight for their rights and remember that they too are a part of the broader civil rights movement. If more self-advocates get involved, people will start to see Supported Decision-Making as something more than something that agencies can bill for. In summary, Supported

Decision-Making is meant to give power back to the individual to make the important decisions they need.

FURTHER RECOMMENDED READING

Finn, Chester, "Group Homes Versus Living in the Community." Published by the Samuel Centre for Social Connectedness, July 28. 2021.

<https://www.socialconnectedness.org/group-homes-versus-living-in-the-community/>.

Lord, Janet E., Katherine N. Guernsey, Joelle M. Balve and Valerie L. Karr. "Human Rights, Yes!" Published by the University of Minnesota Human Rights Resource Center Developed and Coordinated by Blue Law, LLP in partnership with Disabled Peoples' International Funded by Shafallah Center for Children with Special Needs, 2007. <https://hpod.law.harvard.edu/pdf/Human-Rights-Yes.pdf>.

Massachusetts Advocates Standing Strong. "Supported Decision making with Austin and Kim." Published digitally via the Massachusetts Advocates Standing Strong website. <https://www.wearemass.org/supported-decision-making>.