

Max Barrows is Outreach Director for Green Mountain Self-Advocates, a position he has held since 2007. He mentors youth and adults with developmental disabilities to speak up for themselves and become leaders. GMSA is a lead partner of the Self-Advocacy Resource and Technical Assistance Center (SARTAC). Max leads SARTAC's technical assistance team assisting local and state self-advocacy organizations across the nation. Max connects with people on all levels advocating for true-inclusion of people with developmental disabilities. In his work, he advances the message that when you meet an individual with a disability, presume competence. He received a White House Champions of Change award for this work in 2015 and Champion of Equal Opportunity award from the National Association of Councils on Developmental Disabilities in 2019. Max is an accomplished self-advocate from Vermont who served as a board member for Self-Advocates Becoming Empowered from 2008 to 2016. On a personal level, Max has a very high interest in extreme weather and he likes to watch college and professional sports.

Hasan Ko

Hasan is a leader of our work on including people with disabilities from diverse backgrounds. Hasan says, "No matter where we come from, we have the right to be ourselves in our own way." Hasan mentors peers in his local self-advocacy group. He represents GMSA on national projects.

1. Can you talk about your personal experience working with disability policy?

Max:

- When I started working on disability policy, I really wasn't sure how to speak up as much. I wasn't sure about how people would react,
- how they would respond to what I would say.
- I'm glad to say that has changed overtime.
- The self-advocacy movement is a tool for me I use. :
 - It gives me the confidence to speak up.
 - I listen to other self-advocates in local groups to get ideas of what to speak up about at policy meetings.
 - I watch and learn from my peers how to get my points across.
- I have to remind myself that change doesn't come with just hope, we have to work for change to happen.
- I have found out the hard way that in this business we often hear the word "no."
- It doesn't feel good to hear a "no", but I am learning how to take that feeling and turn it into the next action
- it has been a real learning experience for me because I learn from both sides of the fence -
- I put myself in the other person's shoes so I can get at an issue from all sides -
- And finally, as someone who is often representing my peers in a policy meeting,
- I take what I learn and bring it back to our grassroots and listen to their reaction and opinions.

Hasan -

- When I grew up, I wanted to be part of groups that help other people.
- When I joined the self-advocacy movement, it changed how I think about who we should be talking to.
- It opened my mind and I step forward to be part of bigger groups.
- For me I was very happy about working with important people.
- I am very proud of myself because I work with people from all over Vermont and the United States.
- It can be hard to work on a team. You need to learn the rules of the group and how they work together

2. What can states do to make sure that individuals with lived experience ALWAYS have a seat at the policy table?

Hasan

- Every day in life we are learning
- We teach each other. We learn from each other.
- Sometimes, we are not complete
- We have a lot of questions - when we work alone.
- We need each other.
- We are always looking for something to do.
- We are eager to learn something.
- The government needs to be aware of what we are doing.
- They need rule that say we must be at the table.
- We need our powerful allies to help us.
- You need to listen to us as much as you listen to the agencies.
- It must be equal - for us and the agencies

Max

- We encourage state directors to ask themselves, how are we creating opportunities for self-advocates to have a real impact on the services they receive? How can we give people with disabilities a chance to make a difference in our own lives?
- We must think about who is representing our needs. It is important to maintain a balance in voices.
- Self-advocates have a large stake in how agencies representing our interests handle business. We want to be involved at all levels with decisions that impact our lives.
- The disability policy world is buried in written words, there are so many words.
- You need to ask, what is the best way to exchange information?
- Many self-advocates prefer to get and share information directly, either in person or on zoom. When you communicate directly with us, you can see how we really feel.
- Often, you can get more out of the communication in person than you do from writing.
- Another issue with written words is that they can lift people up or put them down
- Often, policies take power away from us. We need to put it back in our hands.
- Words often make us feel like we don't belong here.

Hasan

- The goal is for us to live life in our own way.
- We need to share information and let people know what we do.
- We change a lot. Everyday is changing. So you need to listen all the time.
- By speaking up, we create opportunities for ourselves. Our goal and our dream.

Max:

- Thank you for inviting us to the table. When we are working together, we have found that a person can lead from any chair at the table. You do not necessarily have to be in a certain job with a specific title. Being a leader working to change policies is not about your position or job title. It is about what you do. It is about what actions you take to improve life for people with disabilities.

Hasan

- Help us to get technology. It is very important.
- And, give us information before we meet.
- We need to think about what we want to say.
- It can be very hard to say it on the spot in the meeting.
- And remember, it is all about relationships
- We want to connect with you
- This takes time
- There is no shortcut to making a relationship.

3. What can states do to assist people with lived experience to invite others to the table so that it isn't the same people coming and being invited over and over? Can the state support more experienced people to mentor others? Assist with outreach in partnership, along with transportation and other resources mentioned above?

Max

- Consider working with self-advocacy organizations. We can be helpful.
- We can find people that would be good leaders on a board or committee you have.
- We are eager to provide peer mentoring and leadership training to new members, but we need to be paid to do this.
- The main reason we rely on the same people to go to meetings is because it is a lot of work to explain to a new person what is going on.
- Max: There are a number of barriers that have to be addressed.
- For meetings in person, transportation is a big barrier. So, one tip is to encourage the other professionals coming to a meeting, especially if they represent an agency, they should be bringing self-advocates with them.
- Sometimes we are not confident about how much we know. A person may be reluctant to go to a meeting because they are worried about making a mistake. They worry about how people would respond to them if they go off subject or don't understand. It is hard to raise your hand and say you don't understand. If I do that we fear that the group may think we are not intelligent or that we should know better.
- Sometimes, a person's parents or staff get in the way of them going to a meeting. The parents or staff may not think the meeting is important or they don't believe we are smart enough to contribute.
- There needs to be a commitment to take the time to explain and make sure we understand the purpose of the group. In order to feel welcome, it's important for the individual to know what is going on.
- Frequently, ask us to evaluate our collaborations. We can identify what is working and what can be done better when it comes to accommodations.
- Hasan
- Before I knew about being a leader, it feels like I am on a different side of the world.
- And when I get to work as a leader, it changed how I think about what I do.
- It feels exciting and at the same time I want to do more than they ask me to do.
- I want them to keep calling on me as a leader.
- Sometimes they only look at you when you are doing something with them.
- People need to see how I am a leader in my local group
- In place of us going to a state meeting, they should come to us
- Come to our local group meetings

- As a leader I show other self-advocates what I do

- 4. Any changes in approaches you would like to see? What have you experienced that works you have not mentioned?

- Hasan:
 - I want to see everybody working at their best.
 - Make sure we are doing what we are good at.
 - Tell us what we are good at.
 - This helps us to feel stronger
 - This is a great way to give us hope.

- Max: During meetings, check in often with everyone to make sure we are all on the same page. Take time to recap, and have people debrief.

- Max: Make sure everyone has a chance to share or speak. Be patient with people. Some people communicate differently. Make sure everyone is set before moving to another topic or item.

- Max: It takes time for people to say what is on our minds. That's why it's important to be patient.

- Max: Remember to presume competence. Don't make assumptions about what we can or cannot do. Doug Biklen, a champion of self-advocacy said, "If you want to see competence, it helps if you look for it."

- Hasan - Thank you for listening to us.

- Max - Thank you for all you do to get us the support we rely on to be successful in real life. Thanks for helping us get closer to our dreams by providing equal access and equal opportunities.