

Advocate Voice: A Blog By Max Barrows and Hasan Ko

The DSP Workforce Crisis and Remote Supports

On February 10, 2022, Max Barrows and Hasan Ko met with more than 60 self-advocates from at least 25 states. They discussed what works and what does not work when getting remote support from staff.

All agreed we must be given a choice about meeting with our direct support professionals in person or virtually. And make sure that a person understands when you give us choices. Unfortunately, often during the pandemic, providers did not give us a choice. People with developmental disabilities were pushed to keep working with our direct care workers on zoom all day and all night. We need to get up and move around. When you are working from home, you have to sit on zoom a lot. Many people cannot sit that long.

We taught ourselves during the pandemic how to be independent. It's nice not to have our staff right by our sides all the time. For the first time some of us were given a device and regular access to the internet. People have discovered that we can do stuff, like using a computer without staff. Using headphones blocks out distractions and can allow us to communicate more effectively with our assistants.

It works really well for people who feel more comfortable with talking. We get to be our own person by doing our work, living our lives in our own way inside our homes. During a break, you can take it with the feeling of more privacy to "release energy" knowing you are in your own house. When we are having a hard time, we have our family right there to support us to get through it in ways we may not rely on our staff to do.

It provided lots of flexibility for workers and it helped staff save on their gas. We were often lonely, and it was a way to be involved with staff and see their faces. It helped us prioritize and work on the essential things we need to learn. It's good to be independent.

Of course, it all falls apart when the technology is not working, and your staff are not there to help you figure it out. And some people with disabilities and staff did not have access to phones, tablets or reliable internet. It works better when you transition to working remotely with staff you already know and who are familiar with how to support you. It is hard to meet new staff over the computer and to teach them how to support us. Some new staff had no experience and the only training they received was by watching a video. They may look at us, our disabilities, and only see stereotypes and have no idea how to work for people with disabilities.

Communicating our true feelings can be more difficult while working remotely with staff. Staff can give emotional guidance easier when in person. Over Zoom, it can be difficult for staff to read our emotions. Some staff have their cameras off too long and we wonder what's going on. Some staff get easily distracted when we are sharing our screens and they spend a lot of time looking at their phones.

It's absolutely necessary to get out in the community with staff and that is not happening when working remotely. Sometimes it is essential that staff are with us in person so they can show us what to do and we can practice more easily. Staff being in person when learning something new is a lot more relaxing. And finally, for many people with disabilities it's more difficult to communicate via Zoom. Going forward getting support remotely is an important option as long as we get to decide. We must have a choice about being with our direct support professionals in person or virtually. 🔄

NASDDDS and Green Mountain Self-Advocates (GMSA) began a partnership in 2021 to ensure advocate voices have a seat at the table as we support our members. The mission of GMSA is for people with developmental disabilities to educate peers to take control over their own lives; make decisions; solve problems; and speak for themselves. Another purpose of Green Mountain Self-Advocates is to educate and make the public aware of the strengths, rights, wants, and needs of people with developmental disabilities. Find out more at www.gmsavt.org.



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.



Hasan Ko is a professional at Green Mountain Self Advocates and a leader of their 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.



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