



Green Mountain Self-Advocates
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VT Human Services Committee
April 2, 2020

Hello. I'm Max Barrows.

Thank you so much for reaching out to me to testify. We want to thank each of you for working so hard to do what is best for Vermont. I hope you and your families are doing okay.

I work for Green Mountain Self-Advocates. We are a disability rights organization with more than 600 members with intellectual and developmental disabilities. I'm a person with Autism and I receive developmental services. I receive services to help me with my job.

So, you want to know how my services are going? My services have changed due to the COVID-19 outbreak. Instead of going to my office, I'm working from home. The support I get from an assistant who works with me is done virtually through video on my computer.

Having Autism plays a role in how I understand and cope with changes. Dealing with the COVID-19 outbreak has been an adjustment for me in this regard.

Many people with Autism take things literally. An example of that is that I had to clarify with people that the "Stay at Home" order does not mean you literally have to stay inside their home. I had to let folks know that if they are not sick they can still go outside for as long as they want to, they just need to make sure to stay 6 feet apart from others.

People with disabilities are worried that the police would arrest them if they went outside. The reason for this is because in some parts of the country, law enforcement are being used as part of restricting people from going places and staying outside of their house too long. This is another example of how we are supporting people to get the facts.

During this time of uncertainty, Green Mountain Self-Advocates has been responding to this by doing the following:

1. We have created plain language documents on:
 - [COVID-19 Information by and for People with Disabilities](#)
 - [Tips for Working with Support Staff During the COVID-19](#)
 - [Plain Language Glossary on Words to Know About the Coronavirus](#)

2. For 25 years, GMSA has been supporting 23 peer support groups across the state. On March 17th, we started having zoom meetings 3 times a week geared for people with intellectual and developmental disabilities. These meetings are a mix of presenting information and giving lots of time for people to check in. Also, people come up with topics they want to discuss for future meetings. We have had up to 70 people on these video chats. At night our staff uses Facebook to video chat with up to 8 people at a time.

In general, we want to thank the Developmental Services providers for all they are doing to support us. Most are doing all they can. The problem is the changes are drastic. And people with developmental disabilities are having a hard time understanding what is going on.

Yesterday afternoon DAIL put out guidance for agencies providing Developmental Services. To be honest we are still trying to understand what it says. Here are our concerns.

1. This does not seem to be the time for guidance. DAIL needs to put out rules about how services will be provided and when. We do not agree with DAIL

allowing each agency coming up with their own plan. When self-advocates are on our zoom meetings we hear how things are different. For example, one agency is calling each person everyday whereas another agency has instructed some people to email their case manager if they need help.

2. Once there is a set of basic rules. There needs to be one primary communication strategy. Some agencies are sending letters, some are posting on their websites. Yes it is a good idea to reach out in a variety of ways but there should be one primary place to find the rules.
3. The information from DAIL needs to be in plain language. This is an ongoing issue we have been asking about for years.

Here what we are worried about:

- A. We are alarmed when we read in the NY Times that Alabama and Washington state put in writing that people with severe intellectual disabilities should not be given medical equipment, like ventilators if supplies are limited. We understand that at times doctors have too many people to treat and not enough equipment or personnel to help everyone. We want the state to clearly say that decisions about who gets help should not be based on age or disability status. That is discrimination.
- B. We are hearing that hospitals in some places are not allowing families to be with a sick loved one. Please do what you can to allow people with intellectual disabilities to have family or a support person be with them when hospitalized. If someone is Deaf a hospital provides an interpreter. We may need someone with us to understand what is going on with our health. This is an accommodation just like an interpreter is for someone who is deaf. One parent/guardian told us that if their adult child with a disability gets sick, they are not seeking medical treatment because they do not want the person to die alone. As far we know the person with the disability was not told about this idea.

- C. At our board meeting on Monday, 4 out of 17 self advocates said they wished their agency was checking in with them more often. Again, we have heard that many agencies are checking in on people every day. There needs to be an individual plan made with the person. It should include DAIL's basic rules. It should be in writing. Some agencies have done this. It also needs to include what will happen if the person gets sick or somebody they live with gets sick. If it is in writing a person can get help reviewing it often so they truly know what is going on with their services.

- D. We are worried about people who get services who live alone. We ordered a thermometer for someone yesterday. They thought they had a fever and they couldn't check because they didn't own a thermometer.

- E. Another issue is that agencies should not be just relying on a person to call or text or email them. The agency needs to also initiate the contact on an agreed upon schedule. We helped another person do a 3-way call with their doctor. When we asked them why they didn't email their case manager the person said, "He is home with his kids, and I didn't want to bother him." To keep us safe we can't rely on a person with a disability to be the one to call.

- F. The Department of Health is testing healthcare workers. They should also test home providers and staff. We should also be a top priority to get masks and gloves and other protective supplies.

- G. Before the Coronavirus outbreak, GMSA clearly said that a person with a disability should not be paying their parents to take care of them. But now, during this crisis, if an agency does not send staff to help and a parent has to quit their job to take care of their son or daughter – then now under these circumstances, the state should reimburse the family for the money they are losing in wages because one of the parents had to quit their job. The money in their waiver should be used to cover the lost wages. This is not an option after the Coronavirus crisis.

H. We are worried about losing staff. Turnover is already a problem. We understand that you probably cannot do anything about an agency's personnel policies. However, we think that staff should be able to use sick time during this crisis. It seems unfair to us that some agencies are not allowing staff to use sick time to make up for missed hours.

Thank you again for asking me to testify. During this time, the disability community needs the Vermont legislature to be proactive. The State of Vermont is doing a great job protecting our most vulnerable citizens. We ask that you continue to have our backs during this crisis.

Thank you,

A handwritten signature in cursive script that reads "Max Barrows".

Max Barrows
Outreach Director