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## House Committee on Human Services

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Hello. I'm Max Barrows. I am a person with autism, and I get Developmental Services. I get job support services. I work for Green Mountain Self-Advocates as the Outreach Director.

I am often advocating for more funding for Developmental Services. We work closely with Beth Sightler and other agency directors. I also travel and meet with people with disabilities from other states. They tell me how things are going in their states. I feel lucky to live in Vermont when providers value self-determination. Green Mountain Self-Advocates respects and appreciates the Developmental Services agencies who are for the most part doing a heroic job facing all kinds of challenges. But they struggle because they don't have enough resources to train and supervise staff. They don't have enough money to pay decent wages which results in high staff turnover.

For today, my testimony will focus on what developmental services looks like through my eyes and the eyes of my peers.

At Green Mountain Self-Advocates, we have 23 local support groups all over the state. There are roughly 600 members and almost all of our members get developmental services. I visit each group twice a year. I am a peer and people have known me for 13 years. They trust me. They tell me about some of their challenges.

Providing services that help us get the life we want is complicated. The federal rules say that people who get Developmental Services must be able to make everyday choices for themselves like:

- what we do every day
- who we talk to
- what kinds of relationships we have
- where we spend our time.

The federal rules say providers can't just offer only a few options. We can't be limited to services from 9 to 3 on weekdays. The rules say we must have the same kinds of choices and freedoms that people without disabilities typically have. We need to be free to change our minds, just like everyone else.

Michael Smull, chair of The Learning Community for Person Centered Practices said, "Working in a person-centered way requires that we see the person first, what matters to them, not just what the matter is with them."

The main focus of my services needs to be on my point of view, not someone else's. The focus needs to be on what is **important TO** me from my point of view. This is not always the same as what is **important FOR**

me. My agency and my family are good at knowing what is **important FOR** me. It takes a lot of hard listening to know what is **important TO** me. I need the people in my life to be willing to let me try new things and respect my right to make mistakes.

Now finding a balance between what is Important **TO** a person and what is Important **FOR** a person gets way more complicated when the person has trouble speaking. This is why Green Mountain Self-Advocates feels strongly that we need people on the outside looking in to make sure we are truly being heard. This is a way to know that we are being taken seriously and listened to directly.

The Medicaid Rules from the federal government say the person helping me to do planning and the person doing my needs assessment cannot work for the agency where I get services. Vermont is not following this rule. We understand that agencies need to be involved in our planning. But, we also want a chance to meet with someone outside of our agency to talk about how things are going and listen to what we want for our future.

When it comes to making decisions, this is where it gets tricky because most of us need help. So, the person who helps us make decisions has to be:

- Neutral
- They should not be someone with a whole lot of rules and opinions in their head about what we can and cannot do.
- They need to listen to us
- They cannot have their own agenda

It needs to be somebody who is not getting in our heads

**Here are examples of some of the problems:**

Some people who get services live rich and fulfilling lives. However, many people spend their days doing the same kind of stuff for years. They have few relationships with people who are not paid to be with them.

- The goal of Medicaid Long Term Care services is to get us real lives in the community. But, in some agencies people are spending more time in segregated settings. There is a lack of creativity to build options around a person's interests. Support staff tend to lack the skills needed to support a person to establish natural supports in their communities.
- There are many people who have complaints about their services. These complaints have been ongoing and there is not a sense that it will change. People said they feel like there is nowhere to go to get it resolved.
- Many people if asked will say they want a girlfriend or boyfriend. But, most people are not provided with the education and support they need to date.
- A big issue is the lack of staff. If our staff person is out often we go without. There is nothing we can do about it.
- People are not getting enough support to speak up when being silenced by their families.

- Some people said their case manager was with them for several years and they were like a sister. Others described being bounced around to different case managers all the time (i.e. 3 in 2 years, 4 in 5 years).
- At public hearings held by DAIL we heard parents say they were able to keep an eye on things when their son or daughter was in between case managers. But what about all the people who do not have contact with their families, or the people who feel controlled by their families. Who is watching out for them?

## **Solutions**

Self-advocates like the idea of having someone on the outside of an agency to contact. It would be a safer way to say what problems we are having with an agency. Today, when a person or their staff complain to the higher-ups at an agency they often feel negative tension and are reluctant to speak up.

But, having someone on the outside to call is just part of the solution. Most people who get services do not have the ability to call on their own. We still need other outside people looking in on our lives to make sure our lives are going in a direction we want to.

Green Mountain Self-Advocates supports using peer options to lessen conflicts of interest in case management. We need people to listen to us. We need to hear about our options from a neutral person. Having an individual with a disability as the person listening and explaining options to another individual with disabilities would be very reliable. Having people

who have similar, or almost identical, challenges with services there to assist would be valuable. We need reliable information. We need to know all the options. The information should not be sugar-coated.

Self-advocates have said that it would be helpful to have a peer work with them to prepare for their planning meetings. Some feel it would be beneficial to have peers with them during planning meetings. Having a peer can help us speak up during our meetings. They can help us get meetings back on track when they drift away from what is important to us. The atmosphere feels safer when you have another peer with you.

Other states have trained self-advocates to teach workshops to their peers about person-centered planning and to facilitate planning sessions. At the very least independent case managers should be teamed up with peer advocates when doing assessments, overseeing planning and checking on quality of services.

### **In closing**

People with disabilities can run into challenges with the services they get. When this happens, they can be hesitant to speak up about them due to potential conflict. People need resources where they can go and speak about the issues that they face with their services not working for them. A person should be free from any pressure preventing them from speaking up.