



Green Mountain Self-Advocates  
2 Prospect Street, Suite 6  
Montpelier, VT 05602  
[www.gmsavt.org](http://www.gmsavt.org)

## **GMSA Feedback on Vermont HCBS Conflict of Interest Options – 9/15/2023**

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**#1 Comments from the GMSA board in response to survey questions.** These ideas were shared during a GMSA Board meeting on Zoom on 8.28.2023. There were 19 people from 9 counties who get services from 12 providers.

Green Mountain Self-Advocates (GMSA) has been advocating in support of Conflict-Free Case Management and the HCBS Settings Rule since 2014. These CMS Rules are all about our right to receive services that are truly community-based and that respect our rights. A conflict-free case management system is needed, and we support it. However, we do not support the idea of only contracting with 1 or 2 statewide case management providers.

### **Survey Question 1. Overall, this is a positive option to address conflict-of-interest concerns.**

GMSA Strongly disagrees.

- You are suggesting 1 idea. That is not giving us a choice. There must be more than 1 or 2 case management providers. Find out what works in

other rural states. For example, South Dakota has 4 case management providers,

- Wyoming has at least 70 and Maine has more than 100.
- Find a way to work with small local providers with just a few case managers.
- How much power will case management providers have? One of their roles is quality control. Tell us what they will be able to do if a person is not getting the services they need. In what ways will case managers provide feedback to the state when service providers are being designated and reviewed?
- A new Ombudsman Program is being established for people receiving Developmental Services. They will play an important role in providing
- information that is free of conflicts of interest. The state must clarify how the new case management providers will work with the Ombudsman Program.
- Today independent self-advocacy groups are a vital source of information that is free of conflicts of interest. Green Mountain Self-Advocates seeks opportunities to formalize the role of peer mentors to collaborate with and work alongside Vermont's new case management system.

**Survey Question 2. This option meets the needs of program participants and their families.**

GMSA Strongly disagrees

- We need a detailed description of what case managers will do. It needs to be in plain language.
- Explain the difference between case managers and service coordinators at agencies. More than 3,300 people are in DS. The state must set limits on how many people a case manager works with. We cannot just base this on national averages. Find out what is working in other rural states with residential programs serving less than 6 people. We want a choice of who will be our case manager. Make a rule that we meet in person at least once a month.

- Today we can self, and family manage our services. Explain how this will work in the future. Use the new program to make it easier to self-manage.
- For many people, our agencies hold our money. We heard that will change. We are worried that we will have to pay a fee for this service, even though it used to be something agencies did for free.

**Survey Question 3. This option meets the needs of program providers.**

GMSA neither agrees nor disagrees. There is not enough information to decide

- How much are you going to pay for case management? Where are you going to get the money? We are worried that existing service providers might go out of business once they are not paid for providing case management.
- The state is out of compliance. The state must invest new dollars to establish a new case management system. The existing service providers do not have sufficient resources to manage, train, and supervise direct services. Shifting money from existing service providers to establish and fund a new case management system is not realistic.

**Survey Question 4. In order for this option to work well, we think Vermont will need to:**

Create more formalized opportunities to get peer support from independent entities. One important way to support us to live life in our own way is to make peer support a priority. It is important because people with disabilities connect with each other and share experiences, which is growing up with a disability. We know what we have to face and we know what our peers will have to face. For years the mental health system has recognized, respected, and funded peer support. The field of developmental services needs to include funding peer support as part of Vermont’s response to provide information that is free of conflicts of interest.

The state must ensure that case managers are trained and supervised to:

- Listen to us. Understand our dreams and goals. “Know things about me *that*

*I tell them.”*

- Have experience working with people with developmental disabilities. “Knowing how to talk to me helps me calm down and be present in the moment.”
- Focus on our strengths. “I just want them to let us be. Be happy with us the way we are.”
- Follow CMS rules and guidelines for person-centered planning
- Help us resolve conflicts with guardians and family members. If I have a new idea and other people have different ideas, what will happen? How will we decide?
- Be neutral. Give us information to choose where and how to get our services.
- Check in with us in person once a month.
- Speak and write in plain language. Clearly explain our budgets and state rules.
- Observe us when we are with our DSPs.
- To have a choice of who will be my case manager.
- Work on finding housing options and not just say “no” to an idea because of our behavior. We have been pulled so many times from housing. The agency has a set idea of what housing options should be for us. We need help getting our whole teams on the same page
- Have skills to work effectively with people from any background and who speak any language. People have lots of different parts of who we are. Race, gender, religion, sexual orientation, and more are all part of a person
- The diversity of people working as case managers should more than reflect the diversity of the people who live in our state.
- Be a clear communicator and great team builder who brings people together
- Know about local resources. Help us get the healthcare we need.
- Do quality checking. Make sure our ISA goals are accomplished.
- Work with us on our schedule. Get us the schedule we want.

## **#2 Cultural Competence Concerns from Max Barrows**

My name is Max Barrows. I am the Outreach Director for Green Mountain Self-Advocates. I receive Developmental Services.

Recently, I switched agencies. It got me thinking about what I wanted in my new case manager. My old agency did not provide me with a job coach for 13 months. They keep saying that they don't have anyone to fill in. Nobody came through at all.

Today diversity, equity, and inclusion are buzzwords we often see on a company's website. Many disability service systems are taking a closer look at racial justice.

For years, I got services, but I had no idea if increasing diversity, equity, and inclusion was a priority for the agency. So, when I think about getting a new case manager, I wonder if they can meet all of my needs. In the past when providers have asked me about my life, there are lots of questions about my job, living with my parents, getting healthcare, relaxing, and having fun.

Case managers should be aware of and respect an individual's cultural background. Not everyone grew up on a tree-lined street in Vermont. And so, providers should be aware that each person is different and is a unique individual.

I wonder if my new case manager will specifically ask me about my life as a Black Autistic man living in rural Vermont. It can be uncomfortable living in a society when you have so many identities. It adds to the anxiety I already experience from being autistic.

The brutality towards people of color continues. There have been too many deaths and ongoing violence against Black and Brown people in our country. The next time a Black man is killed by excessive force, I wonder if my case manager will think to call me or stop by to see how I am doing. I get nervous walking by a police car. I get an overall feeling of being nervous because of all of the violent racist events in our world, even though it may not have happened to me directly. But not once have any of my providers ever asked me about that.

Sometimes agencies have a narrow view. They only look at the specific services they are providing. They need to use a wider lens. Ask yourself, are you focused on knowing and understanding me as a whole person? What practical steps will case managers take when monitoring my services to make sure that my

service providers have an understanding of systemic racism? I should not be the one who brings up how I am treated in the world. I'd rather be asked that and not have to bring it up. And that should be the case for others.

A person's services, in a real way, must be tailored to who they are. Another need is for case managers and service providers to get better at addressing needs related to sexual orientation. A self-advocate once told me; "Staff just assume I am straight, and they tell anti-gay jokes in front of me." We need our case managers to work with us to make sure our services and supports are welcoming to all people. When our case managers are educated about systemic discrimination, we feel like they are looking out for us.

Being trauma-sensitive is important, but it goes beyond that. They need to understand intersectionality. Sometimes, it is hard to tell: am I experiencing discrimination because I am Black or is it because I'm autistic?

When I get services from people who feel comfortable bringing up racism and ableism on a regular basis, it gives me a strong message that I will be believed and listened to.

The state should be advised by people of color who get services to develop standards for cross-cultural work. No one should say they cannot help us because we are too complicated. We count on you to help us overcome challenges.

We are not asking case managers to be "experts in somebody else's culture." However, case managers must demonstrate excellence in working and serving people from diverse backgrounds.

**#3 GMSA held 5 COI focus groups with 61 members of local self-advocacy groups from August 30<sup>th</sup> through September 14<sup>th</sup>. The groups discussed what is important to them when getting case management services.**

August 30, 2023. GMSA met with 18 people who get services in **Caledonia County**. They belong to the Vermont Choices self-advocacy group that meets in St. Johnsbury.

- Listen
- Have experience with people with disabilities

- Know what our abilities are
- Give my current goals to my workers, not my old goals
- Watch me at work. Help me get more job support if I need it.
- Come in person. And give me other options of how to meet
- Good communicator
- Come see me when I am with my worker. Work with me on my schedule. Get me the schedule I want.
- Right now, my agency gets my SSI. I tell them when I need money and they give it to me. We need help getting our money when we need it.
- The new case manager companies need to know our state. My case manager needs to know what is going on in my town.
- What will happen if people have different ideas on my team?
- The service coordinator I have now only has 10 other people to help. My new case manager cannot have too many people to help. The state must set limits on how many people a case manager can work with.
- I want an in-person visit every month.

September 11, 2023. Max Barrows met with 8 people who get services in **Lamoille County**. They belong to the GATSA (Getting Acquainted with Self Advocacy) self-advocacy group.

- "We want our case manager to speak up for US. Advocate for what WE need. If we aren't getting something, you need to speak up for us."
- "Support me for what I need. Respect us. Answer if I call and get back to me. LISTEN to me. My case manager should put up with me and support me even if it's not my best day."
- "My case manager does a lot for me. They treat me respectfully."
- "My case manager has been there when I need her. She's supportive."
- "I don't like this change. I don't like talking to someone outside the agency. It is hard to have to explain the situation to another new person."
- "It's confusing to me to have to have two separate people, a Case Manager and a Service Coordinator."

- "Relationships are important. I don't have trust in an outside agency." "It's hard to have a lot of new changes. I've already gone through a lot of case managers. There's always a lack of communication when changing case managers."
- "There are communication issues. I always get new staff without warning."
- "Will my schedule change? I like my schedule; I don't want it to change."
- "Staff turnover is hard, and they DON'T tell you about staff changes."

September 12, 2023. GMSA met in person with 13 people with IDD who get services in **Rutland** County and belong to Self-Advocates Becoming Empowered of Rutland.

- We need accountability;
- They need to be on time for appointments;
- Treat me with respect;
- Be Kind to me
- Be honest – Tell me the real deal
- Communication – call back when they say they will call back
- Meet in person, not on the phone
- Meet at least 1x per month
- Be available in between appointments – have flexible accessibility
- Find resources for me
- Ensure that my services are in place – and that they are working.
- Check on my home provider
- Listen without interruption (me)

On September 13<sup>th</sup> an ally of Speak Up **Addison County** met with 10 people who receive services from Community Associates.

- A case manager who will listen to me and not blame me until they have heard all the facts.
- Uses correct Pronouns
- “likes and understands us” for “who we are”.



- “Don’t judge a book by its cover”
- “has to have a sense of humor”
- “One that helps me out”
- “Kindhearted”
- “Listens and understands my point of View”
- “Respects Me”
- “knows that there are two sides of a story”
- “helps me with personal problems, problem solving”
- “Be able to check in on me when I am sick”
- “helping me use my voice”
- “Listens to me”

September 14, 2023. Max Barrows met in person with 12 people who get services in **Orange and Washington Counties**. They belong to the CAT (Capital Advocates Together) self-advocacy group.

- Make sure I have a support person to take me out into the community
- Help me with my money
- Meet with me 1 time a month at least. I have a meeting this week but I have not heard from my case manager since the beginning of the summer. Now I have to go to the agency to meet. It would be better if they would come to my house.
- Treat me with respect
- Help me applying to Medicaid. Go with me when I have to answer questions and fill out the paperwork.
- They need to know about Medicaid and Social Security. They need to know how to explain it to me so I can understand.
- It should be about me not them.
- My staff person has been bringing her baby to work with me. I do not like that. I want my case manager to stop that.
- Help me with appointments. Help me with questions about my bank account.

- Files paperwork on time. Help send my paystubs to Social Security on time.
- Be person-centered
- Open to change things as needed. Things come up with my health all the time that I need help with.
- There may be more continuity with what the Case Managers do with an outside agency. Unlike now, each agency having their own job responsibilities.

#### **#4 A list of some of the CMS required Person-centered planning standards not reflected in DDS policy.**

CMS has Person-Centered Planning Standards that need to be followed by case managers. Compliance with the person-centered planning standards was required as of March 17, 2014. Many person-centered practices are happening in Vermont. However, the following is a list of some of the CMS standards not reflected in DDS policy, guidance, or quality assurance monitoring. The state must formally address all of the CMS standards for person-centered service plans to be used by HCBS case managers.

There are several sources describing CMS standards for Person Centered Services Plans. The following text used by CMS was taken from:

<http://www.advancingstates.org/sites/nasuaad/files/CMS-Person-Centered%20Planning.pdf>

- *The process should provide necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.*
- *The planning process should only include people chosen by the individual.*
- *Reflects cultural considerations of the individuals.*
- *The meeting is conducted by providing information in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient.*
- *The person-centered service plan must be understandable to the individual receiving services and supports, and the individuals important in supporting*

*him or her. At a minimum, for the written plan to be understandable, it must be written in plain language, and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient.*

- *The person-centered planning process should include strategies for solving conflict or disagreement within the process, including clear conflict-of-interest guidelines for all planning participants.*
- *Individuals must be provided with a clear and accessible alternative dispute resolution process.*
- *Offer informed choices to the individual regarding the services and supports they receive and from whom.*
- *Record the alternative home and community-based settings that were considered by the individual.*
- *The written plan must reflect that the setting in which the individual resides is chosen by the individual.*
- *The State must ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community, including:*
  - *Engage in community life*
  - *Control personal resources*
  - *Receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.*
- *Opportunities to seek employment and work in competitive integrated settings*
- *Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and providers of those services and supports, including natural supports.*
- *Be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individual and providers responsible for its implementation.*
- *Be distributed to the individual and other people involved in the plan.*

**#5 On September 14<sup>th</sup>, 18 people who get DS services participated in a Zoom meeting hosted by HMA. Notes were provided by the live captioner. This is a list of what county GMSA participants live in.**

- Addison – Barbie Hodgdon
- Bennington – Lisa Rudiakov
- Caledonia – Chad Cleverley, Levi Gardner
- Chittenden – Taylor Terry, Pat Gibbons, Marjorie Burns, Nicole Villemaire, David Frye
- Franklin – Randy Lizotte
- Grand Isle – Matthew LeFleur
- Lamoille - Rachel Stevens
- Rutland - Katy Daly, April Gilman
- Washington – Max Barrows, Hillary Christian, Alice Goltz, Kristofer Medina