

State of Vermont

Public Listening Session II

Wednesday, November 4, 2021 | 12pm to 2pm

Meeting Transcript (Edited)

Backus, Ena

I want to emphasize that this is an open public meeting and members of the media may be participating in hearing. The stories today, so although we are not making this recording available. There are other ways that where your stories may be heard around the state as you share them today.

We asked that people try to register in advance to share their experiences and we will call on those who pre registered first and then we'll ask others who are joining the forum to raise their hands if they'd like to contribute.

Uh we'd like to try to keep comments to about 5 minutes.

If you've joined uhm again. If you've joined in you haven't registered you are. Welcome to contribute and we will call on you to raise your hands.

And there is a chat function in this meeting that will be enabled for the purposes of some polling that we'd like to do with the group only but we're not. We're not inviting people to use the chat to communicate with one another.\

Our first speaker is going to be [Speaker 1] -- you have the floor.

[Speaker 1]

Thank you. I'm I'm coming to you from my car today because I'm traveling for work on. Thank you for having me come Full disclosure. I'm currently a resident of Portland, Maine. However, the time period that I'm going to speak about. I was a resident of Vermont and I lived in Vermont for almost my entire life. Born in Vermont, so very invested in in improving the quality of care in the state.

This is hard for me to talk about. I'm not used to being somebody who has a medical condition.

Uh so forgive me if I sound nervous. Uh so in January of 2019 a little over almost 3 years ago. Now I guess it was. I went to the Fanny Allen campus in Colchester because I had stomach pain and I thought that they would take my appendix out.

Uh but I wanted to avoid the emergency room at Fletcher Allen because I know the wait times. There can be long. But they promptly transported me to Fletcher Allen anyway because they saw that I had a small

bowel obstruction and it was at that point that a surgical resident, said oh you probably have Crohn's disease and let me tell you all these traumatic stories about having Crohn's disease. You're going to have surgeries for your entire life and blah blah blah blah, but she couldn't confirm whether I'd Crohn's disease.

Until I had a colonoscopy and I there was no gastroenterologist for me to talk to or consult with it would be awhile.

So, there, I was hospitalized. I was on the Eve of my daughter 's second birthday. In in a panic, I'd never had never had a serious health condition in my life.

And didn't know what was going to happen next I would say. Somewhat complicated delivery those probably 48 hours at Fletcher Allen or some of the most stressful and traumatic and so it's some extent wait times or relative right you could wait a really long time for care.

And and and and maybe 24 hours, 48 hours isn't a long time to wait for care. But it's those moments when you don't know what's happening to your body and nobody will tell you and there's no one to tell you that the surgical resident had no clue what they're talking about.

Uh it's pretty stressful and and I couldn't leave. And until someone was able to come and see me eventually I saw. And in internal medicine resident, UM who could care less about gastroenterology, but was stuck in this rotation. She was may be able to tell me a couple more things. I think I saw a gastro for about 5 minutes. I I asked to be sent home. I was done.

But again, I still didn't have a diagnosis without a colonoscopy. That's the only way to confirm as you can imagine colonoscopies are pretty popular. 'cause everyone has to get them over 50.

Uh so is it getting a colonoscopy in in the Burlington area when you need it for a diagnostic purpose is a gauntlet colonoscopies also by the way are a big moneymaker. They cost about 9000 Bucks 10,000 bucks apiece. So the wheels were turning in my mind about how this all works.

So, like I said, I know diagnosis. I questions about my now chronic illness with no cure that I was told that we live with this for the rest of my life. If I had it but I didn't know.

I ended up just skipping Fletcher Allen and trying to find a private practice. There's only one other private practice that I could go to because there's no competition. Nobody is allowed to compete, Fletcher Allen. I've watched and read the news. The way they fight private practices who want to open up. Uhm outpatient surgical facilities, you know, there's been big fights for that. And so I I was able to get my mic confirming colonoscopy. I did have Crohn's disease, I needed treatment.

And in in April 2019 after we had tried some other things, they prescribed Remicade, which has to be given with an infusion. That's an immunosuppressive. It's been on it's on the market longer than anything

else, I wanted to try it, you can only get that in the infusion center. I was told I'd have to get at the Uvm Cancer Center guess who's busy UVM Cancer Center and guess who's a low priority 'cause I'm not gonna die right away.

day for months. Can I please just have an appointment or we can't give you an appointment until you process it until we process the referral. We can't process. The referral 'cause you're continually at the bottom of the pile because we have cancer patients who need to get this infusion.

And so 6 weeks later, I didn't have an appointment let alone the treatment that I needed and in mid May and in the early hours or what have been what would have been my first day teaching as an adjunct professor at Vermont Law School. I was, I woke up in the middle of night, vomiting because I had another small bowel obstruction. I had to go back to the ER because I still hadn't been treated. ER physician was appalled, but he had seen this a lot before and he said. You really need to talk to the Ombudsperson. This isn't that insane, but I've been seeing us.

Even after that episode I still couldn't get an appointment for my infusion. I've been planning to move to Maine. So I just transferred my car to MGH in Boston.

I'm very privileged educated person, I'm a lawyer by training, I can advocate for myself. That's what I had to do to take care of myself. I can't imagine what happens to people who don't have the privilege and the access and the ability to navigate that I don't know that they don't have what I have.

Uh you know from there, you know, I've heard I heard lots of rumors that I couldn't get my infusion because the drug that I would needed would come from a specialty pharmacy rather than from uvm and uvm wouldn't be able to make a profit on it, I've heard that JVM doesn't make enough money on infusions to make it worthwhile. These are rumors by the way that I heard from health care professionals who are trying to explain to me where I was still going without treatment and whether or not any of this is true this non profit hospital has argued time and again.

And it needs to have a monopoly on care in northwestern Vermont and now central Vermont and on it spreads.

Northern New York so that people have access to the care that they need because otherwise we won't have the specialists ET cetera ET cetera ET cetera. But in this whole time that they've demanded to have a monopoly on the care. I haven't been I wasn't able to get access to a very basic treatment for a frontline drug for chronic condition before landing in the ER again and it's hard not to see the possibility of a profit motive that drove this decision.

I'm horrified to imagine what other people have experienced who can't even read between the lines. The way that I have. I also share this story with my mom and she reminded me that in 2018. The year before. This whole saga began my grandmother died at uvm from complications from untreated post operative. Small bowel obstruction runs in the family.

She complained for months, but couldn't see a specialist and she ended up checking herself into the ER when the pain was so bad and by then, she was septic. She lost 80 pounds. I didn't realize this and I still remember the surgeon, who attempted to save her, talking to us as if it were her fault if she hadn't been treated sooner and it haunts my family wondering if she'd still be here if we could have advocated for better for her.

Backus, Ena

Thank you for sharing your story and for sharing your grandmother story as well.

Dayno, Isaac

Thank you OK our next speaker is gonna be [Speaker 2], The floor is yours.

[Speaker 2]

Yes, this is [Speaker 2] and thank you for the opportunity to relate my experience in my case with the uvm Health

First and foremost. I wanna say how fortunate we are as a state to have the uvm Health Network to meet are varied and often complex health issues.

I know I'm not a typical patient.

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[Speaker 2]

Not getting the specifics, but to explain my perspective, starting in 2012, I developed a serious health issue.

Since then I've wrestled with several more and accumulated a health care team at the help net network of 15 doctors or other professionals.

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[Speaker 2]

And this has expressed itself in the past 3 years. There's some 30 plus medical appointments each of those years.

When do these were routine follow up appointments but many others were not.

Usually my experiences did not involve any significant wait times.

That said, I recently had 2 wait time issues, which were unreasonable and had to be resolved.

In one that was referred by one of my doctors and other specialists appointment came back at 3:00 and a half months out.

I was shocked it was really unacceptable. I contacted my referring doctor and she took it upon herself to resolve it.

Shortly I received the new appointment date 2 weeks out.

The second and this was the follow up appointment was scheduled past the date Medicare required to cover the costs of medical equipment, I needed it.

In this case, I called the doctors scheduler explain the situation and she said. This was the best. He could do. But if I could do a tell him medical that telemedicine appointment, it could be sooner.

Resolved and it was scheduled well within their Medicare time requirement.

You still are still reinforced for me that which I already knew you do need to be your own advocate.

To those of my experience is by far and wide positive.

Finally and it should not go without saying my take my team of 15 were effectively. A team as needed. They did consult each other as one issue would overlap with another.

Again, thank you for the opportunity to comment on this important issue.

Ena Backus

Thank you for sharing.

Dayno, Isaac

[Speaker 3] you our next speaker.

[Speaker 3] (Guest)

Hi everybody can you hear me?

So I my my story is not about myself, but it's about my son to whom I am on full legal Guardian form or about 7 years.

So my son, who is 36 years old now has a severe mental health illness diagnosis.

Ah, he was first diagnosed about 15 years ago and he has been a central client since then.

So for the past decade, his life has been a history of multiple hospitalizations and currently. He is in a psychiatric hospital again.

Can we have more time to experience for him and for us as his family are being hospitalized was the worst out of 15 years of.

Uhm being in exposure to these, he was finally admitted to inpatient psychiatric Ward. On Day 15. That's right 15 of waiting for admission in the emergency Department at the Uvm Medical Center Fletcher Allen.

And also no one else left in hospitalization was involuntarily. He was brought to the emergency Department by South Burlington. Police that happened on August 5th and he was transferred to the hospital late in the afternoon on August 19th.

During these 2 weeks. I was visiting him daily and all these visits were at the emergency Department so every time every day. I try to speak whether it is tough mainly the nurses, sometimes also.

Or like a medical assistant, Slayer so in each and every conversation. Every time I was assured by the personnel that the transfer to the hospital to the inpatient facilities coming shortly.

And because everyone is aware of our situation on because it's bad and everybody is working to resolve it so at first for the first few days few days. That's right. He was assigned a usual emergency Department bed and everyone knows that these semi private beds are only separated from other beds. Just by the curtains nothing else is there so the room big room with curtains has 27.

24 hours, 7 days a week light there is no sound. Proof it's not fully protected from you know for other patients to here and basically observe what's going on and what's going on with him and how he behaves and that was quite erratic, so he was moved to a little more private room inside the emergency Department only after a few days.

When he completely lost his sleep, he was not able to sleep and that's where patients in the mental health crisis with a severe known mental health diagnosis.

So as I mentioned I was only able to speak with the emergency Department nurses.

So Day One Day 2 Day 3 Day 4 Day 7 Day 889. Nothing happens, so meeting with the emergency Department psychiatrist happened after more than 10 days of waiting after few requests of myself and only after I pretty much made it clear up to Central Station in the emergency Department unchoking nursing station.

About this meeting is a little bit overdue in my mind. So, however, even in spite of all that there was no resolution happening until Day 15, when he was finally hospitalized.

So during my visit I have noticed that there were few more patients who seem to have mental health issues simply because they were almost all the private rooms with doors filled and each and every room had a special assistant medical assistant sitting by the door watching the patient in my mind, and in my experience it only happens when.

A patient has mental health crisis and when the crisis is active. This was not the first time when my son has been hospitalized.

But we haven't seen in a while, I speak. I'm speaking for myself in my modern 15 years long, experience with emergency Department emergency hospitalizations.

Uhm I have not seen restoration being as bad as it is now.

I also wanted to mention that the group of people with mental health issues is probably the most underrepresented and least heard and that's partially because not everybody from our mental health.

Mental health off the people one mental health illness can speak for themselves and the Guardians oftentimes are bound with all different privacy policies.

Uhm hipper regulations and everything so this is the reason why you don't really hear. These tourists that that often so I do have a full consent from my son, too.

So I'll talk about it, I'm not happened when he was healthy and I do have guardianship over him. I find this as an opportunity to.

To present the situation to you and that's the reason for me to bring up this story to your attention.

So I also wanted to mention other during all this hassle. Everything a few times, I was told not his hospitalization has been delayed because of the covid vaccination status.

He has pretty severe allergies.

One of the side effects of the medication for the allergy actually is the reason for his mental health issues.

So for him, it's just plain dangerous. He has medical reasons, not to be vaccinated. So I was shocked to learn about the covid vaccination him not being vaccinated, was delaying his hospitalization that was a shock for me, it does sound like.

Pretty awful situation when the person can't speak for themselves and the Guardian who represents him may not even have all the information on hands to represent the person because there was no communication whatsoever from which all and if not be not not near insisting on them, releasing the information talking to me. Talking to at least try to understand what's going on talking to the personnel.

I would not have this information to even present here well. Thank you very much for your attention.

Backus, Ena
Thank you.

Dayno, Isaac
I think that is the end of our speakers have RSVP D. According to our records were on this call so we might just want to move into the the hand, raising section. So folks if you're not familiar with teams. I know it's a new platform for some there should be a little hand in the upper right hand corner of the screen, and then you can click that button to raise your hand and then we will call on you.

Backus, Ena
Thank you Isaac.

And if if the hand button isn't working for anyone for any reason and you would like to speak or share you may may speak up.

Backus, Ena
OK, if if there are no other speakers. AHS - Secretary Teams Room
You know, I'll just I'll just add quickly that I really do appreciate everybody coming forward and and participating in this and I really.

AHS - Secretary
Uhm the stories are heartfelt I mean when you when you hear I'm it just. Come on, you, you wanna do something, as quickly as possible so we'll be looking at the various ways that we can help with the various issues that have been brought to our attention and just want to thank everybody for being brave and talking about the situations that they're in.

Backus, Ena

Thank you I see that [Speaker 3] has her hand raised again.

[Speaker 3] (Guest)

If I can just add one more comment and that's something I I'm just thinking.

Question more than the comment is there any limit on how long a patient can be in the in the emergency Department any patient?

I mean, I understand that there are priorities and I understand that patients say children in any life threatening situation will definitely go first.

And then there are other ways how they prioritize our patients in the queue.

But in in our case, it really seems like uh there should be some kind of limit because if it's constantly someone constantly pushed to the end of the key and they can't wait endlessly endlessly.

So I mean, there are I could make but all these just feels like.

Oh, probably one of the most important to the emergency room environment these days.

[Speaker 3] (Guest)

Thank you.

[Speaker 4]

Thank you. I I if someone wants to take the time to answering this question. I'm happy to wait.

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Mike Fisher

You know, maybe I'll just jump in and and quickly say I don't know of any.

He uh statutory or regulatory rule that limits how long I apologize my camera gets darkened.

Uh how long someone can wait but I want to respond on a human level. It just shouldn't happen.

Come and and we know it's been happening and and.

And I just want to join with you in a recognition of just how horrible it is. When somebody has to wait for

so long for any kind of care but in the case. You described for child for psychiatric care and I'm sure that everybody here would join me in that state.

I I just wanted to reiterate that he's 36 and that kind of puzzles that he's not a young child and not kind of puzzles or not question because I in my experience I do go regularly to the group home where all people have mental health issues, so I talked to them.

[Speaker 3] (Guest)

One of the observations, I made that all these people are they do lose thing with support naturally simply because parents are getting too old and over the past decade. I know if you simply have died and then they are these people. They are at the mercy of this of the system.

So about tragic watching.

And it's like full the children are placed there are parents because they are minors. Parents can advocate for them. But in this situation, it seems like there are 2 many regulations in the process, too much of Teeny tiny details and.

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[Speaker 3] (Guest)

End result is no one is responsible because each move the organization makes sort of violates one of the poses so it. It has become so restrictive that it's not even helping uh also I'm sorry. I'm holding probably the floor. more than I intended but I wanted to mention that I wrote to the state Legislature and I have the email, I can forward the email to you if it helps any.

I did get some responses. I I believe that working together, we can solve it if not completely. But we at least can make it better, so I'm more than willing to do anything I can to help.

Backus, Ena

Thank you. I we would like to receive if you're able to share what you've sent to others, and you can submit that to the email address for this project or through the DF our website and thank you. Not only for your for sharing your story. But for your consideration of of how your contribution can help to address this issue.

Backus, Ena

And it's very generous to be thinking about others in the same situation even as you are experiencing it for yourself and your family so thank you.

Backus, Ena

And now [Speaker 4].

[Speaker 4]

Hi thank you. My name is [Speaker 4] and I actually am a advocate on the helpline at the office of the health care advocate and I wanted to echo [Speaker 3] is concerned about mental health wait times not just when it gets to the point of the emergency room care, which I think that her story and her son story really illustrate well but what we get often

Are the calls from folks? Who are not at crisis yet but recognize that they need mental health services? Which is already a pretty big step. Considering the stigma that comes with a mental health care and mental illness and the wait times, just to get established with a counselor.

Uhm or to get you know psychiatric care to get on medication.

Uh we are uh uh regular call and I think it's particularly.

Uh concerning in my personal life and and my professional life from the hotline for men who finally get to the point where they can accept help and ask for help to be told they have to wait months. That's a serious issue for people of color in Vermont, who experience you know everyday mental health crisis that White Vermonters but also on top of that racism and white supremacy.

Uhm for Queer Vermonters you know, there are a lot of specialties that mental health counselors have that. You can't. It's not somebody you can just you know look in a phone book or or Google folks really need to have a good match and be a good fit for you, it can sometimes even if you can make it point minutes. It can be a long process to find that match of somebody who really works well with you in that relationship. It's really important to maintain.

And I think that there needs to be more investments and more systemic.

Changes made to invest in the front end before we get to that crisis point. It could really do a lot to prevent the wait time crisis in the emergency rooms and the hospital beds.

And I I'm thinking, I'll share one quick anecdote of a story of a caller who called recently moved to Vermont and she moved to either North or South Caro and she called me in the middle like the end of the fall season and the islands are a beautiful place to visit in a beautiful place to be, but are particularly isolating in the winter and she moved in. She was looking for to get established with mental health care and her options were either to drive 45 minutes.

Saint Albans or 45 minutes or an hour down to Burlington for the Howard Center and she moved from a bigger stating couldn't believe that being on the islands, she was her closest option or 45 minutes and even to get into both of those designated agencies is a pretty long time. They're pretty overwhelmed and and that's not even you know the most rural part of our state, so that that call stands out to me because those are those are long treks to Burlington or saying all bins if you're in the.

Islands, especially in winter and I can. I just feel that isolation not color so thank you very much for

letting me share and thanks to arena for sharing her story about her sons until crisis. It's really hard to talk about.

Backus, Ena

Thank you, thank you for sharing as well.

Are there any other participants that would like the opportunity now to share?

And UM, I'll also give the opportunity for any of the members of the team that are working on this investigation. If any of the team members would like to share any comments before we would wrap up the session.

Pieciak, Michael

Well, you know just you know just in the same way. We just sort of summarize from the last session. I mean, you know, I think there's some clear takeaways here, I mean hearing everyone.

Uh we experienced today sort of hit on this point of advocacy either. You know that that you know you almost need to be an advocate for yourself and there's certain people who are able to do that. And there's certain people are not able to do that and have more challenges doing that whether it's because they're going through mental health crises or because they're intimidated by the system or the doctors or the process, which I can understand and appreciate so you know shouldn't have to be that. Way up and then you know, I think the access to mental health was another big theme to this, you know today as well. And both of those themes. You know, I think I think access to mental health came up during our last discussion. I think this advocacy point. Maybe wasn't hit on is sharply in their last session, but I think that's a really important point for us to think about and consider as we continue our work. So just want to thank everybody for for participating today.

Holmes, Jessica A.

And I guess I would just add that thank you for that. You know, these are heart wrenching stories and I. I'm sure you're not alone out there and there's others who may not have even had the courage to come today to share their stories. So I appreciate the courage and sharing your health conditions and your experiences and it's heart wrenching and something does have to change and I the hope is that we're going to be able to do that through the learnings that we do in this investigation and identify some solutions. I just wanted to add that.

Uhm for those of you who are on the call, but didn't you know contribute in this you know uh verbally. Now there's other opportunities to share in written comments and so Isaac. I know if you wanted to share again, where the the portal is to submit written comments to us we read everything and we really appreciate.

Uhm anything that you want to share and if you have something that you think about after this call that you wish you had said again that's another opportunity to send in your feedback.

Backus, Ena

Thank you Jess and thank you Mike as well.

Uhm I think those observations really signaled to me a particular theme and and hopefully that.

Uh uh the The Forum is a place to appreciate this theme, which is that you're not alone. In these experiences even though these experiences can feel very isolating and that's particularly clear to me in having the opportunity to hear from Vermonters both during this session as well as the previous session last week.

And other people have had like experiences and if that's it. It shouldn't be a consolation, but whatsoever, but it is something that I've appreciated through this that that.

Thank you and I'll you know, I see that we've had a couple other people joined so I will make a Last Call in in the event that anyone would like to share at this time, who hasn't had the opportunity to share yet.

Backus, Ena

And then and then again, encourage everyone to share written comment through the portal and we will also be in touch with those who participated to gather your feedback on this survey.

I'm seeing no hands raised or any other signals and so with that. Thank you again for sharing your stories today into contributing to this work.

END OF MEETING