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EPISODE NAME: VSA Vermont: the State Organization on Arts and Disability

Today on Across the Fence we're going to learn about VSA Vermont and a special movie project that's giving voice to a Vermonter with a communication disability. Good afternoon and thanks for joining us; I'm Judy Simpson. Vermont is home to a number of movie projects at any given time that our focus today is on a unique movie with a man named Mark Utter. Mark is a Burlington man with a communication disability that has kept his thoughts trapped in his head for most of his life. He's written a movie called “I am in here.” Joining me is Emily Anderson. Emily is the director of creative performance and cultural acts with VSA Vermont and she is working with Mark on a movie and some fund raising. Welcome and thanks for being with us.

Emily.: Thank you it's wonderful to be here.

Judy.: Let's talk about first of all VSA Vermont.

Emily.: VSA Vermont is a statewide nonprofit arts organization and currently we are reworking our mission statement. Two thoughts I will give you are: my Director, Judy Chalmers says it's the intersection where art meets disability and Mark Utter says VSA gives the power of the arts to people who don't have voices.

Judy.: So tell us about your role.

Emily.: My role as director of creative performance and cultural access I predominately work with adults and high school students who have some kind of cognitive developmental disability.

Judy.: Tell me a little bit about your background that enables you to do this?

Emily.: I used to work with the Bread and Puppet Theater that's what brought me to Vermont. I was a company member in Glover Vermont for eight years and as many people know they are political theater that addresses social and political scenes.

Judy.: How has that helped with the work you're doing now?
Emily.: Over the years at VSA, I have developed a style of theater that really encourages people with disabilities to use different kinds of innovative and interesting theater that combines their stories and their work so that they can basically share with other people.

Judy.: So what is your goal?

Emily.: My goal is that by putting people on stage and we see this over and over again that audiences then get to develop a different view of someone that they might overlook or turn away from. I feel like if we keep creating moments like this that society could probably evolve hopefully evolve to a place where we can celebrate difference instead of condemning it.

Judy.: That's the perfect introduction to the promotional video that you and Mark made with Jim Helts of Green Mountain Video to help with the fund raising for this very special movie called “I am in here.”

I am Mark Utter. I was born with neurological differences that make it hard for me to be a participant in a world with spoken words. When I was young I was moored in an inaccessible sea. I was forever wishing people would realize that I was inside thinking and wanting them to know: I am in here! Locally a man named Pascal arrived looking for some sign of life and my lost boat. My heart leapt at this miracle.

Mark Utter has created a film about his life with a communication disorder. In it we learned that in spite of having access to facilitated communication he experiences many awkward moments. The premise of the typical day in the life of Mark is populated by an array of characters that are real and imaginary. Such as this fellow who I call exact Mark. He represents my mind which doesn't get out much. Mark comes up against social obstacles. Hi we'd like two tickets for the revenge of bloody demons. No retards can see that movie it's like R rated. And through video tricks. I disagree I'm old enough to be your father. And through the art of animation his awful rich inner world is presented.  

I am in here. A view of my daily life with good suggestions for improvement from my intelligent mind.

We would like you to consider what communication means to you. I am Emily Anderson the producer of I am in here and Mark’s communication partner. For the past five years, I've been sitting next to him watching him take his idea of telling his story and turning it into a movie making project. When the movie is finished people are going to be able to appreciate the unique perspective Mark has of our world that's been trapped in his head for a long time. Additionally Mark will have a context which to start conversation with people that help them achieve one of his life pursuits. Finding ways to embrace our different ways of being human. Join our friend Mark--donate generously to our life changing project.

Judy.: That's really incredible. We're going to talk about the fund raising effort in a moment but tell me about your role with Mark as his communication partner.
Emily.: I will start where I started which was with Larry Bissonette. He is a man who is in a film right now called *Wretches and Jabberers* with Tracy Thatcher. It's a documentary where they travel the world and meet other people who use alternative forms of communication. It's a gorgeous movie. It was made here in Vermont and Larry is the first person that I worked with when I moved here after working with the theater 13 years ago. I got a job working with Larry and he's an artist and he has autism and his best way of communicating is through typing but because of his autism he cannot control a lot of his movements. What really helps him is if someone touches his shoulder or the back of his arm and that focuses him so he can type. Working with him just totally blew me away and opened a whole new door to me.

Judy.: I would imagine so. So how did you meet Mark?

Emily.: First I would like to say with Larry what was so interesting was that he seems so strange and you could so easily think this guy's not here and when you sit with him and give him support his brilliant words come out and you realize he's right there. With Mark what happened was he at the same time was taking some theater and puppetry classes that I was teaching for VSA. I knew that he did not speak and was not a verbal person but I could tell something was going on inside and I really wanted him to be able to participate in this play we're writing about this bird that felt really lonely and needed to escape its loneliness. It was the only green bird among a bunch of pink birds. So I said Mark would you like to try typing some lines for this? With some effort he wrote two beautiful lines. I’ll read one of them: “I, the little green bird am tired of so many friendless days in my life. I want to know how it feels to have old, cold lonesome longing for love gone.”

Judy.: That is so sad and really profound, did you have any idea that this going on?

Emily.: No.

Judy.: But you said it took some effort for him to write that.

Emily.: It did and what he has told me since is that when he first tried facilitated communication which is what this supported typing is called he didn't like it. It was tedious it was frustrating and he only could to see it being used kind of in a way where he was writing his schedule or mundane things. But having this opportunity to use it creatively sort of made a spark go off in his head and he realized I want to get better at this and I want to work with this woman. For years he pestered me about doing this project and finally I was like okay let's get started.

Judy.: So what did the work look like?

Emily.: 5-6-7 years ago I'm not sure how long ago we started to meet once a week for 2 hours and we've kept that up for years. What Mark says is:. I wrote my thoughts down for the first time and call them ramblings. A woman got me thinking about the big screen so I assembled them and asked Rusty Dewees to sit with us. He gave us good feedback.

Judy.: That's amazing. What was the feedback?

Emily.: First of all Rusty is just one of many really great advisers and collaborators who have been joining us on this project. I keep finding people and Mark keeps welcoming them in this beautiful way. The Rusty sat with us and read through the ramblings and was like you know
what would be really compelling would be to show you out in the world and how people react to you as you are. So Mark started a new screenplay and decided he wanted to use the premise of the day in his life and populate it with all of the communication obstacles he deals with daily. He wrote a draft we sent it out to a lot of friends for feedback and Mark has been incorporating that feedback into his many revisions. Rusty saw the script read the most recent raft and said Mark great script strong and informative.

Judy.: Nice. It seems like Mark is pretty motivated and you would have to be.

Emily.: Yes he is and I think what is really helped him is that he doesn't think of himself as disabled. Which gives me a stronger foundation than those who have fallen into that trap. It's true Mark’s life circumstances could allow him to just be a passenger and for a lot of us running around having busy lives that might seem like a relief but I think most of us would agree that's not what life is about. What I'm watching daily is Mark has created this project on his own initiative that is allowing him to engage directly with the world and I'm constantly seeing him learning new skills acquiring more knowledge and I'll just give a list of some of the things that I've been watching him do. That is he writes beautiful, engaging and affective emails. Kick starter updates and letters to people. He runs great meetings with funders. He outsources art projects. He's been a great guest speaker at colleges. He's done at least five different colleges.

Judy.: I'm going to interrupt you here because we don't have a whole lot of time. I know Mark has something he wants to tell people in Vermont.

Emily.: Yes. Good people of Vermont I want to thank you in advance for supporting the work Emily and I are doing. I feel it will assist the great state we live in to be celebrated for its forward thinking once again.

Judy.: So how can people help?

Emily.: This evening we will be having that evening with Mark Utter and that's at 7:00 at the off center for dramatic arts in Burlington. Jernigan Pontiac the cabdriver who writes for seven days will be a guest. Its $20.00 at the door. We're also going to be showing our video down in Randolph at the Paramount on Friday. It's great for us to be traveling with Wretches and Jabberers because we feel like Mark is taking writing his own movie using facilitated communication taking the promotion of facilitated communication a step further. Lastly we are ending our kick starter campaign on June 18. We set a goal for $25,000 to be raised by June 18. Many of you know that if you don't raise the money by the deadline you don't get any of the pledges.

Judy.: Where's the website so people can help out.

Emily.: The website is vsavt.org so help us out today and thank you.

Judy.: Thank you so much Emily amazing story.

Emily.: Thank you very much.
Judy.: That's our program for today I'm Judy Simpson will see you again next time on Across the Fence.

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