Literary and Cultural Disability Studies: An Exploration

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Lecture – 10
Interview with Prof. Amy Shuman
Other People’s Stories and Conversations (Disability and Storytelling)

Hello, good evening everyone. Today we have Prof. Amy Shuman with us. Prof. Amy Shuman does not require an introduction. She is a world-famous folklorist, narrative theory specialist and a very fine disability studies scholar. She teaches at Ohio State University. Among many other distinguished awards, she is a Guggenheim fellow. The topic I want to discuss with her the problem of storytelling and I call today's topic as Other People's Stories and Conversation with Amy Shuman.

Why stories? Well, disability is immersed in many narrative universes, disability in itself is a gathering of narrative universes and people ask why, what happened, how it happened? Blind people may ask where is it, who is that and that in turn may prompt newer plots, newer modes of listening, newer modes of connectivities and hence the relevance of the idea of other people's stories. Thanks so much Amy for coming on board here. I feel so privileged to have you here.
The privilege is entirely mine. Thank you for inviting me. So let us begin like this Amy, why people tell stories and what are stories shall we begin that way?

Sure, so I will start with the why. I think people tell stories because they want to understand something. They want to understand the past. They want to understand something that just happened. They want to understand another person or they want to understand themselves. I call that the promise of storytelling is a very compelling promise and it extends to anything from fairy tales or mythologies or religious stories. So, the promise is very different depending on whether the promise is to tell some vital truth about humanity or to explain something that happened yesterday, but nonetheless that is the promise and I do not think we succeed in that promise. I think we often fail which interests me, but I do not think that it stops us from trying. So, I think it is more of a process and it is a dialogue so it involves the teller and the listeners. So, we tell in order to create this relationship among people, among tellers, listeners, future listeners, ourselves. So that is the why do we tell stories part.

What is a story is a simple question that a story tells that something happened that is the simplest definition. Something happened and if you tell it in such a way that you say this happened, if you reverse the order of what you said you would get a different story. So, a story requires some temporal dimension whereas first this happened and then that happened though they are necessarily told in that order, but it requires us to understand some kind of temporality. So that is the really basic definition.

And there are depending on the listener stories change and the storyteller changes, does that happen? Yes, there is quite a bit of interesting research on children telling stories. The idea is that children first get the idea of the temporality before they get the idea of a solution, so they might tell a story, I went to the store, I jumped in a puddle, I bought some candy but you never get any sense of where it is going or what the resolution might be. It might even be that I jumped in a puddle and my boots got wet, but you never find out what happened and whether your boots got dry. So very young children, certainly 2-year-olds can tell stories but by the time children are 8 years old they have figured out how to tell a resolution that is that they have told you a story where there was a problem and it got solved. So that is another definition of story that there is a problem.

And very young children can tell the problem part, but then solving the problem comes a bit later. And of course, people tell stories all through their lives and tell very different kinds of stories in their lifetimes. In Indian schools Amy, I recall children call that moral of the story. So when I tell a young child say 7 or 8, they used to ask me uncle where is the moral of the story? You tell me first.

Right, so the moral of the story is usually an additional explanation. The moral of the story tells you how to understand it and that is even more important. So it is one thing to say my boots were wet, I dried them off. So, you have a problem and a solution and another to say the moral of the story which is what is the purpose of this story, what is it supposed to tell me that is far more important and many people who study narratives believe that is the most important part.

It has been called by one of the narrative scholars whose name is William Labov. William Labov calls it the evaluative part of the story the so what, so-so, every story should answer the question so what, you should not end by saying does not matter. So, the moral is really very important and it is interesting that children learn that so young. So resolution, moral, expectation and all that then make stories travel dynamically and you call it travel.

What does that mean Amy travel of the story? Well, one of the questions that has really interested me most is that question why do stories travel from one teller to another, from different listeners to more tellers to more listeners and what are the restrictions on that who owns the story. Does the story belong to the person who experienced it some would ask or I have asked also does it belong to the person who suffered the experience and what happens when somebody else tells your story?

Do you feel that they have spread the word in a good way or do you feel that they have exploited you by taking your story? This is very important in disability studies, this question of who owns the story. So, I would say yes stories travel, that a good story may be defined by the fact that it travels. If you hear a story and think it is good you are likely to tell it to someone else, so stories travel.

But at the same time, we have claims on our stories and the claim is related to what you were talking about earlier about the moral or the interpretation of the story. So, when stories travel does the moral travel with it or did someone tell the story and give it a new interpretation which is not this interpretation that you might have given it and I would say yes that is what happens is that stories travel. They acquire new morals or new interpretations and they move from one place to another, all kinds of things change and some things remain the same. So when a disabled person feels look you have misrepresented me or misappropriated my story can those claims be validated or how does one respond to such claims in the first place?

So, I think every culture has rules, norms, etiquette for who should tell whose stories. So I will start there and some cultures actually have written these down or have inscribed them in some way in a sense of very familiar understanding of when you should or should not tell something you have heard about someone else, something that is not yours to tell, most cultures have those and there is terrific research on that as well on rumor, gossip and the cultural specific understandings of who should tell whose stories so we have that to go on.

And in addition, though people with disabilities face a different sort of challenge which is that very often people with disabilities are not granted those rights that is that if there are norms and conventions for who should tell whose stories very often people with disabilities are excluded from those. To call attention to that in the United States anyway there is a mantra phrase. I do not know if you have it also there, because it is nothing about us without us, it is a rhyme in English nothing about us without us. And it is very specific to the disability rights movement because people with disabilities are accustomed to being spoken for. No matter whether they are in a doctor's office where they are present and they might be there with a caretaker who is there for mobility issues having nothing to do with cognitive issues or maybe it is cognitive issues they are not given the opportunity to speak for themselves, instead they are spoken for.

This is such a problem for people with disabilities that this phrase has now become this mantra, nothing about us without us. So what can people with disabilities do I think we need to be very vocal, we speak up about the fact that people with disabilities have a right to speak for themselves and can speak for themselves. Even if they have cognitive difficulties, we have to find the way to let them speak for themselves.

So that the burden should be on the listener to figure out what's the way to let this person speak for themselves and there is some very interesting research on that too. A woman named Val Williams who recorded conversations between people with intellectual disabilities and others. A care worker was present usually and the others would listen to what the person with intellectual disabilities said, completely not listen, would hear it but not listen. Then the person with the caregiver would rephrase it or say it again and the person who was listening would pay attention to the caregiver and Val Williams showed in her tape recordings that the person with intellectual disabilities said it perfectly clearly the first time in every case, it just was a matter of listening to them and they were being disregarded because they have intellectual disabilities.

That is true. Well in Indian context nothing about us without us as a mantra in itself is catching up with people who are familiar with western discourse and also who can speak English and connect to it, but the spirit of it the idea of self-assertion, the idea that one ought to speak otherwise it will go out of my control it is there in different modalities in the grassroots disability movements and also they are borrowed from other identity movements such as the Dalit movement and different farmer movements and other identities and so on.

So it is there and one can also add the idea that the ways in which one names oneself, one gives oneself a name, I am blind, I am visually impaired, I am visually challenged or I am A, B and C that now it is becoming clear that how one should call oneself, how one should present one's own story should belong to people themselves, people from outside maybe have to deal with it, maybe you have to connect with it, but not determine the business of naming oneself.

So that seems to be also the work happening at the grassroots and in the academic environments, I mean that is my response to how it happens here. Yes, and it is very interesting that it occurs also with those other movements with the Dalit movement or the farmer's movement and it is very related to storytelling. So, one way to take back the presentation of oneself is to tell one's own story. So that is becoming in a fascinating way, a central part of disability studies that is disability memoir where people with disabilities tell their own stories and tell them in a very self-critical way. There are some problems that you face immediately telling your own story as well it still be taken from you even though you tell it yourself. I just want to mention here that my work on this follows one of my teachers, his name was Erving Goffman. And he wrote a book called the Presentation of Self in Everyday Life that was one of his first books that is about the difficulty of presenting oneself in everyday life. What are the things that compromise the possibility of presenting yourself, tied to that a book he wrote later he wrote a book called Stigma which is about the ways that society labels particular kinds of difference as what he calls a spoiled identity.

So, he is using that a bit tongue in cheek to say that because he does not believe that your identity is spoiled, he is trying to demonstrate the ways that identity gets spoiled by people who stigmatize others. He does not talk enough about disability because that was not his topic but all kinds of stigmatized identities and how they help someone, then if your identity is spoiled because you have a disability, then how do you present yourself in everyday life?

How do you restore your sense of yourself against this other presentation of you? So part of it is with narrative is that for people with disabilities and for many others your own narrative starts to serve as a counternarrative that is there are already narratives about you. So, when we say nothing about us without us it is not that we get to start fresh;

there really is nothing about us without us. The truth is there is already something about us without us and we need to tell a counternarrative because we want to tell our own story to contrast with that story that is already being told about us. And the stories told about people with disabilities are so prolific they are everywhere and they are in religious tracts, they are in fairy tales, they are in all kinds of fiction. People like to tell stories about people with disabilities. We often do not get to find out much about them in the story. They just are a person with a disability and they motivate the plot somehow or they serve as a kind of spoiled identity of some kind, but because there are so many stories about us already then to tell our own story becomes a counternarrative in a good way. Can one call it also counter diagnosis because it was also a critic of diabolic narratives about disability that do the rounds around in fact in a very prolific way. So can one call it that way Amy?

Absolutely. Absolutely that is a good observation and especially about diagnosis I think that very often people with disabilities feel that the story about us is only about our diagnosis and when you say people want to ask questions is it that they want to ask questions about anything other than how we got to be the way we are right the diagnosis question. They want to know often that is the dominant narrative the diagnosis question.

So, disability rights has really made great efforts to try to introduce other kinds of narratives that are not the medicalized or what is usually the problem the pathologized narrative. So, the diagnosis narrative as a narrative one of the problems with it is that the resolution or the moral is overdetermined that is the only possible satisfactory outcome can be a cure which means that people who live without a cure cannot tell their story. Your story does not exist if it is not a story about a cure or overcoming, right.

So the only possible narratives in a pathologized narrative are the diagnosis with the cure, the overcoming narrative or the inspirational narrative. And that inspirational narrative is similarly problematic. So, if the only morals that one can be satisfied with these stories are those then people cannot tell their own stories of their experiences of living day-to-day with a disability that is just the way life is, it is just a different way of life, it is not a pathologized way of life.

That takes us to your framework of small world stories because when one offers counter diagnosis it is not about going the macro way, it is about just my immediate environment, my own small world where things commingle. So, what is this small world and does it have a bearing on stories and their experiences?

So, there is a quite a bit of research right now on what are called small stories. They are not small world stories, they are small stories and that is the narratives of everyday life and that is what you are talking about and really I have spent my whole career looking at these narratives of everyday life, the ways we tell stories in our everyday lives. When I wrote about though I just want to mention when I write about small world stories, I am also writing about something else which is in English in the United States.

Anyway, when you tell a story about a coincidental meeting with someone else like if you and I were to start talking and we would find out that actually we know someone in common who I spend a lot of time in Italy and maybe you have been to Italy and we find out that we know the same person. We might at the end of that story say wow small world, in other words that the world is small because of the coincidence which is a different point than small stories.

So but the small stories, the everyday stories and I prefer to call them everyday stories because I think they are often not small in the sense. I know, I know it is not small. That is okay, many people call them small stories, but I think that is where for me the most interesting work is in disability studies, is in these narratives of everyday life and the ways people describe the things that happen to them and who they tell those stories to, who are you in dialogue with when you tell a particular kind of story.

So in small stories there may not be a listener at all or the listener may be implied it could be a conversation from within or it may a conversation of no consequence but still they are significant in offering counter diagnosis, is that a fair understanding Amy? Do you mean that you are telling the story to yourself? Yes, I mean yourself not in internal conversation but within the four walls, they may not be of bigger consequence, but still they make all the difference to the person telling the story.

Yes, I think those stories do have listeners, I mean I think the stories are the other people in the four walls with you or yourself and I think they have tremendous consequence. I think that we narrate our lives constantly and that is how we make the meaning of them and then when we are unhappy with how we feel about something often the way to approach that is to think about narrating it differently that is to position. And this is a word I use a lot, the word ‘position’. To position yourself and others differently in the story. So, I think that is a large part of what disability rights activists are doing is positioning themselves in another place, not on the sidelines but at the center of their own stories. So, this is very important for small stories. So, if you can position yourself at the center of your story, then you might think differently about the things that are happening to you.

I can give an example here. One of the things that fascinate me that I talk to my students about sometimes is that when my students with disabilities come to the university and live at the university. They experience a kind of autonomy that they have not had before living at home and I love listening to their stories about this because they are very complicated. So, on the one hand they enjoy the autonomy. There are five hands here probably, not one hand, two hand. But so first they enjoy the autonomy. Second, they think deeply about the ways they want to be and do not want to be dependent on others and I think we fail sometimes to listen carefully to the complexity of this people with disabilities, all of us in the world disability or not have to figure out our dependence on others. The people with disabilities have thought about it more deeply and their stories about even very small things have what do you decide to do at a moment when you could rely on someone else, but you choose one or two those stories I think are really important.

So for my students, from deciding if the wheelchair that they have does not fit between the doorway of a particular building or maybe the restroom, or the toilet stall of a particular building what should they do? Should they ask to have the doorway widened, should they get a new wheelchair, should they figure it out somehow and that is a question and who should they ask to help them. So, it can become a disability rights kind of narrative where they are asking for something that they think ought to be changed or it can become a very personal question or the same thing happens.

If they get an inconsequential illness while they are at the university away from home, they have been accustomed to asking they always say it is their mothers but I would say their parents, but they have been accustomed to asking their mothers for help with all things related to their medical needs, do they want to continue to do that maybe that is a good idea. If they do that, do they think that then their mothers will take too much control over other parts of their lives.

Is it possible to have your mother only involved in your medical decision, no, it is not decisions but medical appointments. If the mother is involved in your medical appointments, is she then going to think she can make the decision about them. If she thinks she is involved in your medical appointments, does she also have some control over your eating habits, etc.

So, these narratives that my students tell to each other and to me and other small stories right, the small stories about well I want to ask my mother to send me this food because I cannot get it here, but I really do not want to involve her in my life, especially not in my eating right now. So it would be a narrative right. And those small stories about dependency I think are so rich and so much more so they have greater complexity than anything else.

That I have read about interdependency which is I think a major question we have in our society right now whether it is the former dependency of the colonies on the colonizer and then that kind of autonomy or independence or the mutual interdependence of nations or trading partners. You know the big questions about interdependency I think are not understood with as much complexity as my students. I think understand them in small stories about dependency and autonomy.

Wow, wonderful. I want to say this Amy having heard this from you I think disabled people also work on this very deeply depending on their life courses, stage of life, context and what situation or social climate they are in. For example, for a young person in a college like the ones that you are talking about maybe their sense of pride as individual young persons may be more important. And maybe for a middle-aged person like me the notion of my integrity may be more important and maybe for an elderly person the disability the fear of abandonment may be lurking in the background when they want to make decisions about how to tell stories and revise stories and get things done, I mean by way of dependence, interdependence and autonomy I mean achieving balances between all these three frameworks.

Exactly and I love the way you phrased it. So if we listen to the stories of the elderly for example instead of worrying about so my elderly aunt recently had a very minor car accident. She scraped the side of her car against another car, so no one was hurt but there I just told you a narrative right. My elder aunt scraped the side of her car against another car. So that story can become about many things. It can become about should people her age drive, is she going to hurt someone, you know this time nothing happened but for her I think it was about the fact that she would have to make all of the arrangements to fix the car. The mirror was cracked that is all that happened. So, her narratives are all about fixing the crack in the mirror. They have nothing to do with whether or not she should be driving.

And I will listen endlessly to her telling me all of the stories about getting that mirror fixed and that are her narrative. She does not want me or to start to ask her if she should be driving and that would be a narrative that would violate her sense of her freedom, independence right. But it is also about abandonment in that sense because I think at a deeper level what she needs from me as a listener is to listen to her story.

As her story, it is about the cracked mirror and what do you do if you are 90 years old and your mirror cracks and there is the virus going on so you cannot just call people and have them, drive you somewhere. So my job was to listen to her story about a cracked mirror and all the things she was doing and listen in order to not abandon her. I think what would make her feel abandoned is if I started to ask her if she should still have the car. Do you understand what I am saying? I mean it is so particular. Yeah, I know it can be existentially threatening. Yes exactly. It can be existentially threatening. So the question is for everyone, for all of the people, the college people, the middle age people, the elderly when someone is telling a story what is it for them that is existentially threatening.

So it might be the same question across all groups, but the experience of being young or middle-aged or elderly is so different that what is existentially threatening is different and the narratives are a place for us to pay attention to that. So storytellers may be laying boundaries, implied boundaries beyond which they do not want stories to mutate or travel.

So, my aunt would not be happy if her story about her cracked mirror were told as a story about whether or not she should drive. I think she would be okay with what I am saying or I would not be saying it to you right. I think that she would feel validated, she is probably not going to listen to this interview. There is not a chance, but I feel ethically bound to think about that as I tell it to you as I found I felt ethically bound when I told you the other stories about my students.

I just made stories travel, two times in the last few minutes right. So, I told stories about my students but I told those in a very general way, but still the students who told those stories would recognize themselves in the stories I told and my aunt would definitely recognize herself because as I said she is my aunt. So, I just made stories travel and I told them for what I thought or I am claiming. And you could or other people listening to this could disagree and if you disagree then I think it is very important that you articulate that for yourself if you do not have a chance to write to me about it. But this is very important that we have this conversation about the ethics of how stories travel. So, I was attempting anyway as I always do to be very conscientious about these stories traveling and I am suggesting in both cases that they were for a greater good.

So in the case of the student's stories there was a moral to my story which was that these students in their narratives know a great deal about interdependency and we should listen to them. Similarly, when I told the story about my aunt the moral was that as you said that we should ask how does she experience this as being existentially threatening, this scratch on her mirror of her car.

So, I think we always have to ask when we retell someone else's story we have to ask is the moral traveling with it. If it does not, I mean I do not think my aunt is very interested in the issues I am raising here today for example. I mean I could call her up on the phone right now and ask her and I think she would say no not particularly and I would do that if you like me to, I will call her. But she would say she is not particularly interested but she would say if you are interested that is fine. I mean she would not feel violated. So, it is not the case that we share that the interpretation is shared right. It is more important that we ask whether the changed interpretation is a violation or exploitation. So, it is going to happen that we change that when we tell a story we tell it with a new moral or a new interpretation or in a new context where it has a different meaning.

The question is does that new meaning violate or exploit the person, so that is what happens with inspiration narrative and I am sure many of the people listening already know about that. But if you tell me a story about something that you did and you feel good about having done it and then I tell that story as an inspirational story I am violating you in that particular different interpretation.

So, we are starting to name some of the ways that the stories told by people with disabilities violate people with disabilities. We have starting to have some names for them overcoming, inspiration and we are starting to recognize that those are interpretive moves that violate the person or exploit the person. So, that there are some inherent problems maybe with transvaluation or allegorization. Because when stories travel beyond the storyteller, they can also gain allegorical dimensions and what that does I learned from your writing is that they also make the stories stay nowhere. They are everywhere but they are de-contextualized and they do not have the value that was attached in the first place, is that a fair understanding Amy?

Yes, this is the question that interests me most. You have it absolutely correctly. Whenever we tell someone else's story outside of the context of that person we allegorize it. An allegorization which makes a story larger than life. So whenever we make some person story larger than life, larger than the context in which it happened we allegorize it and we do this all the time. This is we love stories that are larger than life that is what is most compelling is stories that are larger than life.

My aunt's story is not larger than life, no one is going to repeat it because it is not even interesting that my aunt scraped the mirror of her car and then she had to figure out what to do about it, not a very, it is a very small story. But stories that can be allegorized are very compelling to us and whenever we allegorize the allegorization is always potentially dangerous. We do it all the time that is what most fiction is, most fiction is allegory. It is larger than life stories. It is taking a particular story and saying this has bigger meaning than just this person. This story has a larger meaning so to say that stories are larger than life allegorizes them and subjects them to that danger that the philosopher Jacques Derrida described it as a dangerous supplement. The additional meaning, the supplementary meaning that you give to it that makes it larger than life is always dangerous. It is also very compelling. So, we are not going to stop doing it, I am not suggesting that we should or that we can, but rather I think we need to pay attention to the ways that it is dangerous and understand it in particular with relation to disability. And maybe allegorization also puts a ban on newer travel possibilities because it is like saying this is the ultimate place, it is like river joining an ocean. I mean now that it has a transcendental meaning there is a moratorium one can have from this point and therefore it is a final resting place. I am just making it, I am just dramatizing it, but I thought that is what they do.

That is true and that is very interesting that I love that idea that stories can have this kind of final resting place where that meaning takes hold. I think that is true that particular meanings can take hold that is probably a good example of that is pity narratives that once the pity narrative takes hold it is like the river joining the ocean and no further movement can take place. I think that is very true. Right, I cannot believe that an hour is almost over I mean it is an experience talking to you Amy. I learned so much and so will be the listeners.

But do you have a few words to add and then probably will say bye to our listeners. I will say that the more we pay attention to the narratives that are told by people with disabilities the better we will understand and be able to reclaim that presentation of self. So, I think it was good that you spoke about the small stories that we need to pay attention to those stories. Not just the big memoirs that are published by people with disabilities which are also very helpful that is another place where we find the reclamation of narratives about disability is in memoir. We did not get a chance to talk about how that can be complicated, both can be complicated, but it is a place to start. So, I will end there. Thank you so much Amy. Thank you so much.