

Disability Deep Dive Episode 106: More Than a Moment: Jhónelle Bean on Tourette's, Communities of Color, and Advocacy

Jodi Beckstine (00:00:12):

What happens when a public controversy forces people to confront race, disability, harm and misunderstanding all at once, and what gets lost when the conversation moves faster than care, context or truth? Today we're talking with Jhónelle Bean about the BAFTA Tourette's controversy, public response, and what it means to advocate at the intersection of race and disability.

Keith Casebonne (00:00:37):

Welcome back to Disability Deep Dive, where we explore disability through culture, media, policy and lived experience. Earlier this year at the BAFTA Film Awards, John Davidson, whose life story inspired the film, I Swear, and who has Tourette syndrome, involuntarily shouted the N-word while Michael B. Jordan and Delroy Lindo were on stage presenting. The moment quickly sparked backlash and public debate, including questions about Tourette syndrome, racism, media responsibility and how harm gets handled in real time.

Jodi Beckstine (00:01:11):

Jhónelle is a disability advocate and ASL interpreter living with Tourette syndrome. We wanted to have this conversation with someone who could bring care, lived experience and real nuance to a moment that too often gets flattened online.

Keith Casebonne (00:01:23):

Yep. Let's get started. Before we jump in, I'm Keith, a white man with brown eyes, brown hair, a graying beard and a gray shirt.

Jodi Beckstine (00:01:31):

I'm Jodi, a white female with dark blonde hair, blue eyes and glasses, and I'm wearing a black and gray sweatshirt.

Keith Casebonne (00:01:39):

Jhónelle, if you're comfortable, we'd love to invite you to visually describe yourself for our listeners as well.

Jhónelle Bean (00:01:43):

Sure. My name is Jhónelle. I'm a Black woman wearing a dark green shirt with glasses.

Jodi Beckstine (00:01:50):

Right.

Keith Casebonne (00:01:50):

Excellent.

Jodi Beckstine (00:01:51):

Well, to start us off, could you introduce yourself to our listeners and share a little bit about who you are, the work you do, and how you came into disability advocacy?

Jhónelle Bean (00:02:01):

My name is Jhónelle. I'm 31 years. I'm in Texas. I've been, I guess, working within the disability community for many years, from working at a camp for children and adults with disabilities to working with deaf children in schools to being a disability advocate for Disability Rights Texas. Through all of that, I feel like my Tourette advocacy naturally came out of that based on my own experience, creating videos and educating people online.

Keith Casebonne (00:02:38):

Excellent. That's a good foundation for understanding where your advocacy skills come from. You've spoken publicly about living with Tourette syndrome and you've built an online presence around advocacy and education. What led you to start sharing your experience more openly and what did you want people to better understand from the beginning?

Jhónelle Bean (00:03:01):

Yeah, I feel like for me in terms of sharing my experience online, I definitely feel like it came from a space of realizing that there wasn't a lot of people that looks like me that were talking about having Tourette syndrome. It is still, I feel, a pretty misunderstood condition. A lot of people think that's, quote, unquote, "something only white people get," or only males have it, not females. I've read things like that. I know whenever I was experiencing symptoms of Tourette syndrome, when I was younger, I would try to see online what people were talking about regarding the condition, people's lived experiences, and there really was not, again, a lot of people that looked like me.

(00:03:50):

I guess the thought popped up with me thinking if I now have the opportunity to talk about it and help somebody else who looks like me who's trying to find resources online or information, then I can be that person that I needed when I was younger. I feel like that's some of what started it, and then also, making friends with other Tourette syndrome advocates, and again, just seeing the certain things that they would talk about that I realized my experience was different because I was a Black woman. So I was able to... I think those two things combined give me enough motivation to be like, "Yeah, I think I'll talk about it. I'll share online."

Jodi Beckstine (00:04:35):

Yeah, it's a big deal. Once you start speaking publicly about your disability, you can see gaps in it and you can also see the assumptions that people are making about disabilities. When you talk to people online or in your everyday life, what are some of the most common misconceptions that you see when people talk about Tourette syndrome?

Jhónelle Bean (00:05:03):

Yeah, where do I start? I'll talk about some of the misconceptions, and then I also want to, I guess, describe a bit more what Tourette syndrome really is and what that can look like.

Keith Casebonne (00:05:15):

Please.

Jhónelle Bean (00:05:16):

Some common misconceptions that I get or hear are that, number one, it's actually voluntary and it's more of a behavioral thing that you just need self-control. There's a misconception that everybody with Tourette syndrome has coprolalia, which is the tic that causes you to say obscene words or socially inappropriate words such as curse words, slurs, things like that, and if you don't do that, then you don't have Tourette syndrome, and that only kids have it. It's not really something adults have. I feel like, again, there's a lot, but those are probably the top three that I've seen online that I've heard in terms of things people just assume. And then again, like I mentioned earlier, that only males have it or only white people have it, and that's it.

(00:06:05):

Tourette syndrome is a neurological condition, so it's not behavioral, it's something within your brain. We are part of one of the conditions that's under the neurodivergent umbrella

because of that. It causes involuntary movements or sounds called tics, not with a K, T-I-C-S. That's how you differentiate it between the bug. That could look like, I'm sure if viewers are listening or watching me already seen or heard me tic, that can look like blinking, making different sounds like clearing your throat. There are more simple tics, moving your head, snapping, really just any movement, honestly, or any sound.

(00:06:51):

And then for tics that are a bit more complex, it might be for motor tics and movement tics might look a bit more intentional versus me just moving my head or my eyes, which sometimes people think that's intentional, too, but I might look a bit more like if somebody maybe is jumping up and down or running, some people have running tics, which can be super dangerous. And then for more complex vocal tics, there might be sentences, phrases. Again, things that seem more intentional, people assume, "Oh, they're saying that to me. They're talking to me." And then obviously there are a bit more complex tics in both of those categories where it comes to things like I was talking about coprolalia with obscene or inappropriate words. And then there's also copropraxia, super fancy word, but it's the same thing, but that's more inappropriate gestures.

(00:07:49):

So that is what Tourette syndrome look like. Obviously with that, because it is a neurological condition, there is a bit of a spectrum, so there are some people that have obviously more severe cases, which typically gets a lot of social media attention, but the majority of people have more mild to moderate, I guess, conditions where there are times that I've met people and they haven't noticed that I've had Tourette's or they didn't know that I had Tourette's until maybe later on once I mentioned it and they're like, "Wait, what do you mean?" Then once they start thinking about it, they're like, "Oh, that doesn't make sense. I was wondering why you were doing," whatever, fill in the blank. "I was wondering why you're blinking your eyes. I was wondering why you were," doing whatever, and then it makes sense to them. So that's a very brief scenario or a brief synopsis of what Tourette syndrome is.

Keith Casebonne (00:08:40):

Excellent. No, that's great, and that really gives a lot of context to the whole discussion about it. You also talked about some of the myths. It's certainly one thing to deal with these myths in everyday life and it could be another thing to watch them explode across the internet, right? Public misunderstanding moves so fast, especially when people are reacting before they understand things fully or get the full context, which I think is a great transition to talk a little bit about the BAFTA awards. A lot of people encountered this topic

recently through the BAFTA award controversy. When you watched that unfold, what stood out to you most about how the public was responding, and what do you feel was missing from that conversation?

Jhónelle Bean (00:09:30):

It's very interesting. I guess to give people an example of how I took it, whenever talk about it online first ramped up, again, I'm friends with several Tourette advocates, so we have a group chat, there were some people that shared in our thread and said, "Hey, have y'all seen this? People are talking about it online. Seems like it's getting popular." At the time I hadn't heard about it yet because I think it was that night that it happened. At the same time, I had another video from three years ago that was being shared online and it was something somewhat similar where somebody made a TikTok making a joke about when .it was a Black person who gave a joke saying when the kid with Tourette's says the N-word and you finally get your chance, and then he dramatically punches the camera, and I responded to that. That video, people were saying, "Okay, this is kind of similar," and they were referencing it to the BAFTAs.

(00:10:35):

From then, once I opened my phone and looked at people's responses online, again, being someone who is both Black and has Tourette syndrome and is in both communities, it was sad to see people's responses on both ends. It was sad to see people that were just assuming, "Oh, well, he did that on purpose. He doesn't have Tourette syndrome." "Well, Tourette syndrome's not going to make you say the N-word." "Well, how come he didn't say anything else?" "How come..." all the things. Then on the other end, it was a lot of people saying like, "Oh, well, he has Tourette's. You're too sensitive." "Black people are always trying to police who could say what." "This man literally has a disability. Give it a break, give it a rest."

(00:11:20):

I'm like, "Okay, I can see..." Again, I'm literally in both, I can see it from both spaces. I can imagine what it is like going to an event, if I was John Davidson going to an event, because that is my life where I'm like, okay, there's going to be a lot of people, there might be cameras or there might be recording, it might be on social media, I'm already going through a mental checklist of things like, okay, well, I wonder if I'll be near the front, I'll wonder if I'll be on camera. I hope that we're not super close together if I'm ticcing. I don't want to bother people. This is the mental checklist that I deal with all the time. So I can imagine that, and then also being told, "Oh, don't worry, this is edited. We got you," and then them choosing not to edit that out.

(00:12:13):

But then also as a Black person, I can also sit there and go through that checklist of like, "Okay, this is an event. I don't really know what the situation's going to look like. How many other Black people are there going to be? If I'm my true authentic self, is it going to be seen as too much?" I can literally see on both ends because I go through both of these checklists all the time. That also was a reason that I thought, okay, maybe I should make a video specifically about this incident and this situation because there is a lot of nuance to it and people are either only hearing from Black people who are upset or white people with Tourette syndrome who are upset and people forget that there is intersectionality. There are people of color with Tourette Syndrome. We exist. There are Black people with Tourette syndrome. We exist. So that is why I made that video.

Keith Casebonne (00:13:03):

Yeah. I think to add to it feels like the person most at fault is whoever was the one responsible for editing the live broadcast, and why is that individual choosing apparently what to edit and what not to edit? What does that say and what does that...

Jhónelle Bean (00:13:24):

Correct.

Keith Casebonne (00:13:25):

Everyone seems to be ignoring that aspect of it, not everyone, because I know you didn't. You specifically mentioned that in your video.

Jhónelle Bean (00:13:31):

Yeah. I have said that.

Keith Casebonne (00:13:32):

Yeah, but a lot of people seem to have missed that point, not realizing that many other things were said because the individual has Tourette and can't help it, but they were just editing along the way. Why would someone choose to leave that in? That's where I think everyone just kind of goes, "What is happening here?"

Jhónelle Bean (00:13:52):

Right. I feel like some of those details about how much of his other tics were edited out, when that happened, who was in control, who told them, "Hey, don't leave that in," and

they left it, all those details didn't come until days later, maybe almost a week later. Obviously with people's initial reaction, it's just with the limited knowledge and information that they know and that they have. Again, I feel like just in general with the internet, they don't always hold a lot of space for nuance. They don't always hold a lot of space for understanding. It's pretty much extreme one side, extreme the other.

(00:14:32):

So that's also, I guess, a typical challenge that deal with, I guess with posting on social media, discussing things, anything that takes nuance or understanding of both sides to say, "Hey, yes, this person does have Tourette syndrome. Just because he said that with two Black people on stage does not mean it's intentional. There are certain things that do trigger tics. It's both more simple tics and then also more complex tics. Specifically with coprolalia, you have triggers. Your brain says, "What is the most inappropriate thing to say?" Something that you should not say, something that is very against who you are and that's what you say, but then also on the other side, yes, it is fine for Black people to be upset because, again, we're constantly policed in how we should feel about any incident involving us in the media.

(00:15:21):

And then again, once we learn they left that intentionally but took out other tics of his, took out other coprolalia tics of him with other slurs that he said but left that one in, there is a need for people to be upset and want change from that. You can't just sit here and say, "Oh, he's just really... so you just need to get over it," because again, there are other people that did have control and weren't in control to edit that out just like they edited out other slurs, just like they edited out other tics, but they purposely left that in. There is a need for that as well.

Jodi Beckstine (00:15:59):

Absolutely. I think that moment exposed that there was more than one kind of harm that was happening in that moment, and your TikTok that you did about it, you spoke about the need to hold complexity in that moment. As a Black woman living with Tourette syndrome, what did that controversy reveal about the way race and disability get talked about together or even ignored together?

Jhónelle Bean (00:16:32):

I definitely do think it gets ignored more so, or maybe not fully ignored, but people just don't even think about it as an option, whether that's just because I feel like there's

multiple factors to it. I feel like a lot of times any conditions, mental health situations, anything like that within communities, I would say the Black community, because I can speak on that, but I also have other friends in other communities that have shared similar experiences, when things like that pop up within their community, it's not necessarily something that's always talked about or always accepted. "Oh, no, you're fine. You don't have anxiety. You just need to relax."

(00:17:16):

I know for me, it took me 18 years before I finally got an official diagnosis when I first had symptoms because it was seen as, "Oh, no, you're fine. You just move around. YOU're hyper. Just calm down, sit down." So I think because of that, not a lot of people do speak up about it and talk about it because it's not something that you're told to accept or something that is seen as a neutral or positive experience to have a disability. Then because of that complexity, other people who are not part of that community just assume, "Oh, this is not something people deal with," and then because of that, when it comes back to your own community, when somebody does have something or does have a disability, they say, "Oh, no, we didn't get that. That's white people's [inaudible 00:18:01]. We don't have that."

(00:18:03):

Unfortunately, that is the cycle that I've seen, and because of that, I think the discussion about intersectionality with race and disability or race, disability and my gender, all of that combined doesn't always get taken into consideration. So I won't necessarily say it's purposefully ignored. Sometimes it is, but I feel like sometimes it's just not even taken into consideration. Even people that are within the Tourette syndrome community I've had talks with about things and, yes, there is a similar struggle we share with the condition sometimes with the way the public reacts, but my experience, obviously everybody's experience is different, but my experience has an added layer that sometimes when I've shared things that they've even said, "Oh, I didn't even think about that."

(00:18:56):

For example, typically, again, when we're out in public, there's the mental checklist we're doing with our tics, and tics, again, it's a bit of a spectrum, and because of that, it also means you have some good days, some bad days, some good moments and bad moments, just like any other chronic condition. I know if I'm out at a restaurant and I'm ticcing a lot or out in movie theaters that I'm ticcing a lot, that's going to cause me more anxiety, which is a trigger for more tics, fun fact, and that's the thing I feel like everybody with Tourette Syndrome experiences and like, "Oh, I completely get it." I completely get it,

being anxious around a lot of people, being anxious in situations where you're supposed to be still, where you're supposed to be quiet and you cannot control it.

(00:19:40):

But then I also talk about the added layer of, okay, that fear and that anxiety you have, I also experience on a greater level when I'm around law enforcement because, will they 100% understand me if I say, "Oh no, I'm so sorry. I didn't mean to do that. That's involuntary," or are they not going to even pay attention? There's already people that think that when I have tics with my eyes where I'm blinking them or moving my head to the side that I'm rolling my eyes and that I have an attitude, would they assume that exact same thing of my friend with Tourette syndrome that's white? So that's another added layer to the situation.

(00:20:24):

If I do run into law enforcement and I am ticcing and they're looking at me, figuring out what I'm doing, are they going to just take my word for it that, oh, this is an involuntary condition, or are they going to automatically have a certain stereotype and assume it's something else like, oh, she must be on drugs. She's tweaking out. You know what I mean?

Keith Casebonne (00:20:39):

Yeah.

Jhónelle Bean (00:20:40):

These are other things that people, even though we could both be women, we could both have Tourette syndrome, we could both be around similar ages or live in a similar demographic area, but there's that added layer that I experience because of that or because of my race from people outside the community, people within the community, because again, that's white people stuff, what do you mean? So it definitely is something that a lot of people I feel like either ignore or don't even take into consideration.

Keith Casebonne (00:21:13):

Yeah. As you already mentioned, nuance is not the internet's forte, and sometimes in real life, it's not people's forte. It's got to be black or white, hot or cold. A lot of what you're talking about points to the bigger question about what responsibility looks like. For viewers and listeners who want to respond with a little more care, a little more understanding, what does thoughtful support actually look like to you, especially when the conversation involves Tourette syndrome, racism, and the real harm that public moments can cause?

Jhónelle Bean (00:21:49):

Sorry. Yeah, I definitely think it is important to listen to people's lived experiences. I know there was just even in general, a bit of an increase in tics around COVID and a little bit after that. A lot of people are like, "Oh, it's just because everybody's watching it, it's popular right now in the internet and everybody randomly has it," versus people already having that condition and it, I guess in a way lying dormant and then the stress of COVID and routine changes bringing that out. But again, people weren't listened to, so I feel like that is a good example of something, everybody was experiencing COVID at the same time, everybody's stressed, everybody's other chronic conditions were getting worse, but then now that people's Tourette symptoms are getting worse or now they have this, it's like, "Oh, well, this is because of the internet." I think that is another great example of an area where people could have been believed with their lived experiences.

(00:22:48):

Then there was also people that, because there's other conditions where you can have tics, not just Tourette syndrome, so there's other tic disorders and other conditions that people are like, "Oh, well, you're just trying to be like Tourette's." There's so many things that I see sometimes online, it is very frustrating. Even in the fight for advocacy and education, sometimes I feel like you get one step forward and then you see several comments like that and you feel like you're not making any progress.

(00:23:14):

I would definitely say to listen to people's lived experiences, especially people that have some sort of intersectionality, some other type of identity that complicates things or has other factors that play into their disability or has other factors that play into their race or play into their gender or sexual orientation, whatever that intersectionality looks like. Again, even if you don't understand it, because there still are some people and they're like, "No, that seems really intentional. I really think they did that on purpose," and just not understanding that, I don't necessarily know because I can't change people's mind. You're not in my body to know what it feels like when I have a tic, and I can try to explain it to you the best I can, but there's not one example that is absolutely perfect to compare what that feels like.

(00:24:08):

There's people have tried, "It's kind of like this, but not exactly. It's kind of like if you have to sneeze where you feel [inaudible 00:24:14] coming, but not exactly. Kind of like when you hold in a cough and you could control it a little bit, but then as soon as the cough comes

out, you're coughing over, but not really." There's so many different examples, but nothing fits it exactly. So I understand people are not going to fully understand what it feels like.

(00:24:29):

I think, again, the best thing to do is listen to people's lived experiences with empathy and an open mind to believe them. I feel like that's the biggest thing. Typically, unfortunately, a lot of times people don't always, well, not everybody, but some people don't always care to understand situations or believe situations until it affects them or someone close to them. So again, the best thing I think is just to listen to people's lived experiences with empathy and compassion and understanding and an open mind.

Jodi Beckstine (00:25:06):

Well, I'm really grateful for how grounded and generous you've been in this conversation. It feels like a meaningful place to shift to our second segment that we do. We talk about media and disability spaces. It's called the Deep Cut. We always ask our guests if there's a book, a TV show, a film or even a song that maybe resonate with you lately or that you'd like to share with our listeners.

Jhónelle Bean (00:25:38):

Yeah. I've been thinking about this. Does the book or movie or TV show have to be related to disability or is this just in general?

Jodi Beckstine (00:25:47):

Just in general, something that resonates with you that you'd like to share with other people.

Jhónelle Bean (00:25:51):

I'm a reader, reading recently. I'm trying to remember. One I read last year that was really good, I guess this does incorporate disability, is a book. I'm going to actually look up the person's name because I don't want to just say the title and not say the author. Let me see. Okay. The book is called Get A Life, Chloe Brown by Talia Hibbert, and it's a three-part series. It's like a romance fiction. A lot of times the series is not part one, part two, part three. A lot of times it's maybe their siblings or friends, and so this book is this person's story, the second book is that person's story, the third book is the last person's story.

Jodi Beckstine (00:26:43):

Nice. Okay.

Jhónelle Bean (00:26:43):

They're sisters-

Keith Casebonne (00:26:43):

That's cool.

Jhónelle Bean (00:26:47):

... so this is about the three different sisters. This first book is about Chloe Brown, who's trying to get her life together and she has a couple different chronic illnesses, and it talks about the nuance, it includes the nuance of that with sometimes she's like, "I just have to have things in meal preps. So if it's a harder day that I can just go in the kitchen, sit on my stool that I keep there and warm it up and be able to eat." Also, navigating that with life, trying to get a job, navigating that with dating, finding love.

(00:27:17):

So I did appreciate that book. It's called Get A Life, Chloe Brown by Talia Hibbert. I believe Talia Hibbert is from the UK, so there might be some words in there that you're like, "Wait, what?" I do remember being like, "Wait, what is that [inaudible 00:27:33]?"

Jodi Beckstine (00:27:32):

I like that. Fantastic.

Jhónelle Bean (00:27:32):

I do like that.

Jodi Beckstine (00:27:35):

Oh, I'll have to look it up and check it out.

Keith Casebonne (00:27:37):

Yeah, excellent, for sure. Well, Jhónelle, thank you so much for being with us today and bringing so much honesty and care to this conversation.

Jhónelle Bean (00:27:46):

Of course. Thank you all for having me.

Jodi Beckstine (00:27:47):

We really appreciate you.

Jhónelle Bean (00:27:48):

If people that are listening have any questions or anything like that, feel free to DM me.

Jodi Beckstine (00:27:53):

Fantastic. We'll have all of her social media in the description.

Jhónelle Bean (00:27:58):

Cool. Awesome. Thank you guys so much.

Keith Casebonne (00:28:00):

Thank you.

Jodi Beckstine (00:28:03):

Keep diving with us. This week's Deep Cut is just ahead.

Keith Casebonne (00:28:09):

For today's Deep Cut, we're talking about What's Eating Gilbert Grape, the 1993 film based on the novel by Peter Hedges. Before we get into it, though, we want to give you a content note. This movie includes outdated language, disability stereotypes, body shaming, misogynistic comments and ableist terms. Some of the language and attitudes reflect the early 1990s, and a lot has changed since then in how we talk about disability, family care, body size and dignity.

Jodi Beckstine (00:28:39):

We want to be clear, we're not looking at this movie as if it gets everything right. It does not. There are parts that are tender and memorable and there are parts that are truly uncomfortable to watch now. The story follows Gilbert Grape, a young man living in a small town in Iowa with his family. His father has died by suicide. His mother Bonnie is grieving and rarely leaves the house. His sisters are trying to manage their own lives and his younger brother, Arnie, is a person with an intellectual disability who needs support. Gilbert is loving at times, resentful at times, and clearly overwhelmed.

Keith Casebonne (00:29:13):

Today we're going to talk about what still works in this film, what feels outdated, and where the movie asks for sympathy without always giving every character the dignity they

deserve. One of the first things that stands out is how stuck Gilbert feels. He's only in his 20s, but he's carrying so much responsibility. When you watched him, did you feel sympathy for him or frustration or a little of both?

Jodi Beckstine (00:29:42):

A little bit of both. I had sympathy for him because he is young and he's carrying the responsibilities that no one at that age should have to carry alone. You could feel how trapped he and his sisters feel in that town, in their own home, in the roles that they're expected to play in the family, but I found myself very frustrated with him, especially about the way that he talks about his mother, the way he's flippant about what she's actually going through. His resentment of her makes sense in the emotional, but that doesn't mean he should be cruel.

(00:30:34):

I had a really hard time wrapping my brain around him doing some of the things and making some of the choices he made, but I also felt he's a very layered character, but he didn't come that way in the film. It is based on a book. I have not read the book, so I don't know how well the author portrayed that character, but in the film he felt very flat. We would just get to the edge of something and they would change the scene. He didn't come across as a hero or a victim to me. He is just this character that's just moving the plot along a little bit.

Keith Casebonne (00:31:18):

Yeah, I know. I agree. I would've liked to have seen a little more effort put into examining some of his actions on both sides of things and finding out what's motivating him and why and, I don't know, just a little bit deeper, and they didn't really do that. I agree.

Jodi Beckstine (00:31:37):

Some of the characters would say stuff like, "You remind me of your dad here or there." Why? What exactly is reminding you of the father?

Keith Casebonne (00:31:43):

Correct. Good point.

Jodi Beckstine (00:31:45):

Especially knowing that the father then commits suicide. Is he on the road to that? Is he making those same decisions and choices? Are the same things happening to him? So that bothered me, but it makes him a complicated character because he clearly loves his

brother, but he also seems angry and frustrated at everyone around him. When he talks about his mother and those cruel comments about her body, it's hard to listen to. Do you think the movie wants us to question Gilbert's cruelty or does it let him off a little too easy?

Keith Casebonne (00:32:25):

I think similar to what you were just saying, it's really hard to say one way or the other, because again, they don't really... If they examine things like bad things he did and he talked about it and was just like that I'm overwhelmed or this affected me the wrong way and I reacted poorly, I should have thought about it differently or should have said something differently, but they never really show that level of growth, I guess. If you look at the character in the beginning and at the end, there's been growth, but the process of getting there throughout is muddy and it's hard to pinpoint how he grew.

(00:33:11):

I don't know. Yeah, the film shows the pain, but it doesn't really challenge the harm that he's causing people. His comments are cruel about his mom's body, and sometimes you're not sure if the film is saying that it's understandable because he's overwhelmed or is it just inexcusable because you should never talk about someone that way, mother or a stranger, whoever, it doesn't matter. So it's hard to decide whether the movie wants to see him as flawed or are we just supposed to feel sorry for him.

Jodi Beckstine (00:33:50):

Yeah. He's a hard character to get behind and root for in the film.

Keith Casebonne (00:33:57):

Yeah, I totally agree. Well, Bonnie, Gilbert's mother is one of the hardest parts of the movie to talk about because the film, it gives her real grief, but it also turns her body into a spectacle. How did that land for you when you're watching it now?

Jodi Beckstine (00:34:16):

Well, the movie, when you hear someone talk about or bring the movie up, they usually talk about Arnie's character played by Leonardo DiCaprio. That's usually the gist of it. She is this also thing that's happening, but it was a hard watch for me for her maybe now years later from when it first came out. Clearly she's grieving. She's lost her husband. I don't think the family ever fully recovered from that loss. Therapy probably was not even in their minds of something that they need to do to work through that, and she isolated herself not only in her home, I feel like she isolated herself in her body.

(00:35:05):

She's going through a real pain, but she's never framed in that context. She's framed as through the lens of other people's opinion of her, their disgust of her, their embarrassment of her, their curiosity of her, and we never see the flip side, really. There's, again, starts of moments, but it never quite gets there. Her body is this own thing. It's something that Gilbert resents, it's something the town stares at, and it feels like the director wanted you to just be shocked seeing her. I didn't feel that way. I saw a woman who was distressed and grieving.

(00:35:59):

There are moments where she is upset in anger. There's moments where she gets really determined, and they're so fleeting and not really dived into and focused on that it's, again, she's just superficial character there that's just one more thing that Gilbert has to deal with as opposed to a living, grieving person that deserves more.

Keith Casebonne (00:36:31):

Well, and the only real mention of her past is that, oh, she was so pretty and she was so vibrant or whatever, but they don't really talk about, oh, she was very active in the town or she had lots of friends. It's all about her looks. It's all like, "Oh, she used to be pretty," and now, well, oh, my gosh, now there's something different. It's all focused on that, and I really hated that because, okay, I'm sure the idea is that obviously the suicide of her husband put her in a bad place, she gained weight. Okay, that happens to people, but the idea that she just went from pretty to an overweight individual who now won't leave the house, I don't know, tell me more. There's got to be some more depth in there than that, and they really didn't offer that.

Jodi Beckstine (00:37:22):

Yeah, and how her grieving affected her family. We see them having to take care of Arnie, them having to do the things in the home, like bringing the kitchen table into where she's at, but everything was so surface that it really bothered me. I think they could have really delved a lot deeper into that.

(00:37:47):

There's a scene where she goes into town to get Arnie and, in my opinion, she's doing something that's very brave and loving. It takes a lot of courage. It takes a lot of physicality for her to get out of the house and go downtown where she hasn't been for years. But the reaction we get, we spend so little time talking about how brave that is and how loving and

what it takes for her to do that, and it's more about, look at everyone stare, look at everyone gather, and then you see on the ride back home, you see how it affected her. You can see the depression and the shame and the guilt come across her, and then we just move on to another scene.

(00:38:38):

That's it. That's all you get is that minute in the car of her reaction and then we're past it. Again, I keep harping on this point, there's so much there. There's so much material there that they could have worked with and really done justice to that character, and they didn't.

Keith Casebonne (00:39:00):

Yeah, I agree. Her walk into town, like you said, it's an act of care and courage, and all they really focus on is that the townspeople are watching and whispering and laughing and, "Oh, my God, she's out of the house. Look at that." It's just, I don't know, everything, it just feels shallow. Again, I didn't read the book, you didn't read the book, maybe they treated this a lot better in the book, I sure hope they did, but in the movie, it's just watered down too much and it shows how shame can be created by the community around the person, not just by the person's own feelings, but I wish they developed it and really moved into it a little bit more. Yeah.

Jodi Beckstine (00:39:51):

That's an important point of view that they completely just missed the opportunity on.

Keith Casebonne (00:39:55):

I agree, I agree. Well, let's shift focus to Arnie, Gilbert's brother. Arnie is such a memorable character and Leonardo DiCaprio's performance certainly got a lot of attention, but the movie never clearly names Arnie's disability and sometimes it treats him more like a source of chaos or emotion for the other characters. What do you think viewers should keep in mind?

Jodi Beckstine (00:40:20):

I agree that he just was a plot device rather than a character. He is a person and has his own lived experience, but was just a symbol for the stress that Gilbert had, the struggle that the family was going through. The dad committed suicide and they have this disabled brother that they have to take care of. Oh, how horrible. I think Leonardo for the time period did the best he could. I've read that he went places and he talked to people and talked to people about their lived experiences, talked to family, talked to disabled individuals to

wrap his brain around this character, but again, the writing and the directing in the movie did not give him the depth of character. It was more the depth of him came from the reaction of other characters to him and to situations.

(00:41:31):

They don't tell us what his disability is flat out, and I think it matters because leaving something like that vague can make the person seem less like a full person and more of a collection of maybe behaviors that are just, again, a plot device to create tension and sympathy and moments. I think people should watch it with care. Even though his performance was good, the framing of it and the disability that Arnie had is definitely very dated, and you just got to keep that in mind when watching it.

Keith Casebonne (00:42:19):

Yeah. I appreciate that he did the research and he tried to do a performance that was accurate but respectful. I'll be honest, I don't remember what I felt when I first saw it years and years ago. I really don't remember anything specific about how I felt when I first... but when I saw it again a few days ago or so, I just felt this awful cringey feeling inside, because again, it's an able-bodied person portraying an individual with a disability, and whether he meant it or not, at first it felt a little over the top and almost farcical in a way.

(00:43:07):

I don't know, it just reminds me why we don't really see this anymore. This is not thankfully something that you see in movies anymore, that representation, because I don't think you can successfully do it. There's an emotional power to the performance, but I think the framing, the writing, the acting, I don't know, you can still question it and try to understand it, and I don't know that I fully did.

Jodi Beckstine (00:43:41):

Yeah. Well, where do you think there's moments that they may have got something right about Arnie or where maybe did they completely fall short for his character? Are there any moments that stand out for you?

Keith Casebonne (00:43:59):

Yeah, there's a couple things. First of all, he is happy. He's funny at times and he certainly loves his family. You can tell he loves Gilbert. I think those things made him feel very human and were sweet and make you smile. I would also say that there's a scene where Gilbert thinks he'll get himself out of the tub and he's helping to give him a bath and he gets

out of the tub and will dry off, and then it turns out he literally was in the water, now freezing cold water, all night long because he didn't take the steps.

(00:44:35):

That was one of the very, very few moments where I felt bad. I really felt like the portrayal was emotional and sensitive and, oh, my God, this happened, and it felt real because it didn't feel over the top. It felt nuanced. That was, to me, an exception, actually, for the character, but I felt a lot there, too, I'll say. But again, it still overall feels like it centers on other people's burdens with him than it does his own experience.

Jodi Beckstine (00:45:10):

I think the girl that they met that was passing through, I think she had the best reactions to Arnie. He was just a boy she met. He had said something that Gilbert said, "Oh, that's rude." Like, "You can't come to my party" or "You're not invited to my party," and Gilbert was like, "Arnie, don't say that. That's rude." She was all like, "He's being honest." I liked her reactions more than anybody, his whole family that's lived with him his whole life. I just felt like she was just more in tune with Arnie than anyone else, so I really liked her portrayal in it.

Keith Casebonne (00:45:52):

I agree 100%. Yeah. In some ways, I think she was the most down-to-earth, real character in the movie.

Jodi Beckstine (00:45:56):

Yeah. Absolutely.

Keith Casebonne (00:46:00):

Well, there's a moment where Gilbert is asked what he wants and he can barely answer. So it tells us a lot about him. Why do you think that question is so hard for him, what he wants?

Jodi Beckstine (00:46:11):

I think because this is where we tentatively dig into Gilbert just a little bit, he's responding to everyone else's needs. He takes care of Arnie. His mother needs to be taken care of. He's holding the house together. He's bringing home an income. Thinking about himself is probably way, way, way down on the list of things. He feels stuck where he's at and no future or relief in sight, but I think that shows really how young he is. He's acting like

someone who's older, but emotionally and mentally, he's not older. He's just now becoming an adult. He's in his early 20s, but he hasn't even grown into his own life. I think he struggles to kind of... I think a lot of caregivers do this, too. You almost feel selfish for wanting something else or wanting a break-

Keith Casebonne (00:47:20):

Oh, sure.

Jodi Beckstine (00:47:20):

... or wanting anything beyond what's happening in your life, but again, this is where I feel like they totally failed that character. We had moments to really dig in and really press that question on him and cause this growth by him thinking about this. I think he does in the movie, we really don't follow that in the plot. I wish they had stayed on that a little bit longer because I think it could have revealed such a depth to his character.

Keith Casebonne (00:47:57):

Yeah, I agree. It could have really helped expose some of I guess the challenges with, you've mentioned caregiving, but also poverty and small-town expectations and things like that that maybe have narrowed his sense of possibility. He doesn't really know what options he has because maybe this is all he knows. Likely it's what he knows and he hasn't really experienced a whole lot else. I think that meeting the travelers, the young lady and her grandmother who come from somewhere else, we aren't really aware, we can't necessarily say that they come from a big city or wealth or we have no idea, but they certainly seem a little more worldly, subtle, but they probably are a little more worldly-wise, if you will, than Gilbert and his family, which I think is both probably attractive to him and scary to him.

(00:48:54):

But again, they don't really go into it. These are just my assumptions. This is just how I, oh, I felt like that's probably what's happening, but they never really address it. You could see he's got a mixed attitude about, sometimes he's happy to be with them, sometimes he's scared and runs away. Oh, why? Tell us more.

Jodi Beckstine (00:49:16):

Yeah. And he has the relationship with an older woman in the movie, if you want to call it a relationship.

Keith Casebonne (00:49:21):

Sure, sure.

Jodi Beckstine (00:49:23):

One line that stuck with me is she said, "I chose you because you would never leave." That was a moment. That was so good, and it was just kind of there, and then we moved on.

Keith Casebonne (00:49:35):

And then gone.

Jodi Beckstine (00:49:36):

Yep. Commercial break, moving on to the next thing. So it was very frustrating. I have these moments come and then, gone.

Keith Casebonne (00:49:45):

For sure. Yeah.

Jodi Beckstine (00:49:47):

There's a moment when Gilbert becomes physically violent with Arnie, and that scene is painful. We've seen Gilbert protect him and care for him and watch over him. What do you think the movie is trying to show in that moment?

Keith Casebonne (00:50:04):

Yeah. I guess Gilbert's reaching a breaking point. He's had too much at that point. It doesn't excuse the violence.

Jodi Beckstine (00:50:13):

Absolutely.

Keith Casebonne (00:50:15):

It should never lead to that. One thing we do know about Gilbert is he's overwhelmed and feels like he's the sole provider in so many ways. Is he the only one in the family with a job?

Jodi Beckstine (00:50:34):

I think so. I think the older sister does the cleaning and cooking. The younger one goes to school, and he brings home income.

Keith Casebonne (00:50:40):

Yeah. So he's the only one working.

Jodi Beckstine (00:50:42):

But again, we don't know that for sure because they didn't-

Keith Casebonne (00:50:45):

Exactly.

Jodi Beckstine (00:50:46):

... really delve into these other characters.

Keith Casebonne (00:50:48):

Right. No, exactly, exactly. So yeah, again, it's all these things piling up and, okay, yeah, you can reach a breaking point. Understandable. Absolutely understandable, but to strike out at Arnie... Arnie's hurt. He's a person hurt in that moment, and that needs to be clear, called out. It's important to show that. I guess it's showing what happens when one person is given too much responsibility without support, but again, I feel like it's another action in the movie, another consequence in the movie that's not, again, really addressed as it could be.

Jodi Beckstine (00:51:31):

Yeah. It just shows the immaturity of Gilbert, not knowing how to handle his feelings, not knowing how to even ask for help for himself, taking on those burdens. They address it a little bit, but there's no big moment where it's discussed about how that happened, why it happened, why it shouldn't happen. It's just like, "Yeah, I did that, and I'm sorry." Again, I don't even think he said he was sorry. It was just like, "I did that," and...

Keith Casebonne (00:52:13):

I don't really remember. Yeah. I would think, again, it should be memorable, so the fact that I don't remember, yeah, probably didn't. Yeah.

Jodi Beckstine (00:52:21):

It's sad.

Keith Casebonne (00:52:21):

Gosh. Well, okay, so near the end, Bonnie, the mother, climbs the stairs to a bedroom that she hasn't used in years, and then she passes away. After so much of the movie treating

her body as something that people stare at, Gilbert decides that instead of just trying to remove her from the house, she's on the second floor, it would mean, I don't know, a crane or some... it was going to be a spectacle, and again, another public gathering where they're talking and whispering and joking, but he makes a decision that they're not going to have that. What do you think about that choice?

Jodi Beckstine (00:53:05):

I think it was one of the most emotionally complicated parts of the film. It's devastating that it takes her death for Gilbert to finally protect her dignity. He was so flippant about it earlier in the film, but on the other hand, it also tells us he finally understands maybe how cruel he's been and how cruel the world has been to her. For the most part, she was treated like something people had the right to comment on like, "You got yourself into this situation. What do you expect?" When he decides that he's not going to let that become a spectacle, the one sister says, she calls it out, the younger one, that for her, it's embarrassment for herself. I don't know that it was embarrassment for her mother that she was saying it, but it dawned, I think, on Gilbert that she's right. This is going to be a big thing.

(00:54:22):

To me, it was Gilbert as an act of love to her, an act of maybe the guilt he has felt for what he's done in protecting her, that this is the last moment he has to protect her and give her dignity, and he chose to do it. It's uncomfortable, but the burning of the house I think was a little extreme.

Keith Casebonne (00:54:54):

Sure.

Jodi Beckstine (00:54:54):

I think doing that makes it feel more like a release, which I don't necessarily agree with that choice, but I think in the end, we were talking about that arc of the character, I think he got from A to Z. It was in the middle, but Z, at that point, there's a problem I have with the ending ending, which we'll talk about, but I think at that point, he had the character arc.

(00:55:28):

But again, at the end of the movie, it seems like everyone just moved on to this different life. The sisters go their own way, Gilbert and Arnie end up going with Becky and her grandmother, and it felt to me like now that that one burden's gone, we can go live the great

life that we want. I don't know that that's what they were meaning it to be, but that's how it felt to me. One thing that was holding us back and holding us down is gone, and now we can go live the lives that we want to live, which is sad to me.

Keith Casebonne (00:56:09):

Yeah, I agree. It's like we watched this family stuck the whole movie and then, I don't know. With burning down the house and the ending and all, I think a good word is that it all felt very convenient. I feel like the decision to burn the house was probably, it felt, again, I haven't read the book. I'm sure it's probably in the book, but it felt like the Hollywood extremism or whatever. Is it really the best thing you could have done? Is there really no other way that you could have maybe helped remove her from the house with dignity and compassion? I don't know. That just made me wonder what's going on here.

(00:57:03):

Then like you said, everyone now suddenly is like, "Okay, yay, we are going to move on." Really? Again, it's very convenient and it's just like, okay, the trap is gone because the house and the mom are gone? Again, it oversimplifies things. It makes the mom seem like less of a person again and more just a burden. I don't know, I didn't really like it. Again, it just felt convenient like, here's how we wrap it up.

Jodi Beckstine (00:57:34):

Yeah. They pulled all the furniture out of the house into the yard. Didn't anyone go, "Wait a minute, what is going on?"

Keith Casebonne (00:57:42):

I was thinking, you can't claim it was an accident with all the furniture out in front of the house.

Jodi Beckstine (00:57:47):

No insurance for you. The other part is, what did they do for a year? Because they show Becky and the grandmother coming, so it's been a year because it's an annual thing.

Keith Casebonne (00:57:56):

Where have they been? Yeah.

Jodi Beckstine (00:57:57):

So where have they been for a year? What have they been doing? That was not told. I don't know, it just wrapped up weird, but I came into-

Keith Casebonne (00:58:06):

It did.

Jodi Beckstine (00:58:07):

... this deep dive thinking I was going to really be talking about Arnie the whole time, because that's what we know about Gilbert Grape-

Keith Casebonne (00:58:15):

Me, too, yeah.

Jodi Beckstine (00:58:15):

... but I came away with, yes, Arnie was there, he was just a plot device. To me, maybe being a middle-aged woman, this mother's story was just so much more intriguing to me and felt like it was more the root of the story than his brother Arnie was.

Keith Casebonne (00:58:38):

I agree 100%. I felt the same way. Yeah, it's definitely not just you. I was feeling the same way. It wasn't the original reason why I felt like we were watching and going to comment on the movie and it totally changed. Yeah. I don't know, it's interesting. It was an interesting ending in the sense that, not interesting in a fun way, interesting in a, the movie's over, I'm just like, "What have we learned? What has happened? Is there a point?" I never really felt that there was, unfortunately.

Jodi Beckstine (00:59:12):

Yeah. It's a shame.

Keith Casebonne (00:59:14):

It is. Well, What's Eating Gilbert Grape is, it's one of those movies that people remember as emotional and moving, and it's true, it is, but watching it now brings up a lot of questions about disability, body shame, family responsibility, and whose pain does the story actually take seriously.

Jodi Beckstine (00:59:33):

Yeah. There are moments of real tenderness in the film, especially in the relationship between Gilbert and Arnie, but there are also choices that feel dated and harmful now, and that's why it's worth revisiting, not to dismiss it completely and not to praise it without question, but to look at it honestly.

Keith Casebonne (00:59:50):

Yeah, because media can move us and still get things wrong. This movie gives us a chance to talk about how much has changed, what still needs to change and why dignity matters in every part of a story, not only at the end.

Jodi Beckstine (01:00:05):

That's our conversation with Jhónelle Bean. Today we talked about Tourette syndrome, what people often misunderstand about it, and why education still matters so much.

Keith Casebonne (01:00:14):

Today's Deep Cut, our conversation about What's Eating Gilbert Grape gave us a great chance to look at how disability, caregiving, grief, body shame and family responsibility were represented in the early '90s and how those choices land now.

Jodi Beckstine (01:00:29):

Thanks for listening to Disability Deep Dive. You can find our episodes wherever you get your podcasts, and you can watch us on YouTube.

Keith Casebonne (01:00:36):

We'll be back soon with another conversation that keeps disability at the center of the story.

Jodi Beckstine (01:00:40):

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