

Director Dr. Pratap Rughani attended *Documenting Disability Policy Politics and the Personal* at University of Leicester November 18 2015 for a screening of his film *Justine* followed by a discussion with Dr E. Anna Claydon of the Department of Media and Communication University of Leicester. The day started with a debate on politics and policy and disability followed by the film screening and discussion.

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Anna Claydon (AC), Pratap Rughani (PR)

(AC)

Thank you very much for letting us show *Justine* as part of today's event Pratap. I think everybody agrees that was very very interesting, and ties in a lot with some of the comments that Emma was making earlier as part of the debate doesn't it, so have a sense of connection in there. I'm going to ask Pratap three areas for questions but everybody do get involved and chip in with any questions you have as well at any point. We both academics and we're used to working and doing research within an academic context and we know that research ethics are such an important part of when we're engaging with any research with that rather cold medical phrase "human subjects" but one of the things about making film is of course that ethics are a core thing there. I think one of the things that you know you notice yourself in the synopsis for the film was that the question of ethics was very key to how you approached making *Justine* so could you open a bit more on that?

(PR)

So the question's about research ethics?

(AC)

Yes, and production ethics.

(PR)

I mean it's an area that really interests me and typically in a documentary film we work with the notion of consent, and even informed consent, and that has an important history that goes back to the Nuremberg trials and the dispensation at the end of the Second World War, and allocated the detail and the philosophy of that but it basically means that there needs to be some kind of bond of trust between makers and subjects. You know typically you work with this notion of informed consent. Well when I was approached to think about this what really interested me, was how do you work in terms of consent, - how do you work with the notion of consent with somebody who's not able to give their consent in a way we would normally understand it. And that seemed a really really important question and it made me think well why don't I see much work - by work I mean films media stuff in the public square - about people like *Justine*. She has advanced neurological disorders so that is very important to me that we don't name her in terms of her medical conditions. So then that was the challenge I suppose, was ethically how do you then work when on the basis hopefully of connection with somebody but you're not able through language anyway to check out with them what's going on and to reach notions of informed consent, in the way that the law would understand it. The law would say, I mean we obviously satisfied all the legal requirements, the law would say, well you go to the parent or guardian get their consent and then you're done. Okay well that might deal with the law but in a way

that only takes you so far. Justine is not her mom, or her brother, or her dad, all those wonderful people around her - she's her own person. How could film start to intuit and respond to the experience of another, when we don't yet have an example with consent - a legal framework to really talk about how to work with people with what's called, you know who are not wired in the same way as the so called "neurotypical". So that that really interested me and it made me wonder is that one of the reasons why these sorts of experiences are all but excluded certainly from what you see in mainstream broadcast documentary practice.

(AC)

I think we do see within the film the way in which Justine is responding to the camera, the way that she starts to interact with you, in a way that shows it's part of the conversation. I think one of the problems that we often have in filmmaking is the way in which people for whom parental consent has been given are not recognized as having their own identity and their own authority. I think what starts to come through is because of Justine is allowing you to film her, for example frequently when she's on her own, looking pensive, looking concerned about something, she allows you into that space, so start to see how she is actually giving you consent by what she chooses to show you. Is that one way that you think about it?

(PR)

Yeah I mean that would be the best, that would be the most positive reading of it. I want to mention it a very fine woman in her organization who you may well know a Kate Adams, and Project Artworks and she's really pioneered work around artists and disability and has developed her own methodologies and so on, and when she asked me to think about this I was very drawn to it. but also aware of my own ignorance in a new and really interesting way for me. Because I don't, for example, have people with the conditions like this in my own family and or my circle, and so it led me to think well , who am I to do this work? And to start to answer that question for me meant training with Kate, and spending time with people of quite a range of neurologies and seeing how we could respond to each other and on the basis of that I then felt a little bit more equipped to bring whatever skills and opportunities I've had into this arena. I'm not sure if I answered your question though.

(AC)

No, we all go around about route. Yes.

(Audience question, off-mic. indistinct) ... Was there any pushing you away at that time?

(PR)

Yes. What's your name? Andy. Thanks for your question Andy this great question. So that I remember my first meeting with Justine very vividly, and I think I was a lot more nervous than she was. I'd done about a year of exploring and thinking and the workshops I mentioned before then, so I felt reasonably equipped, but I had no idea whether she would accept me or the camera or both and how it would work. In the event, when I met her she was very warm towards me, and from what I could gather I was seeking - I asked her mom if I could have the camera not switched on but in the room and talked to her about that - because I wanted to establish me and the camera at the same time, and then work out how to seek permission. And I moved away from this notion of consent and started to fracture into notions of assent and dissent, because I couldn't be confident that the way that when I expressed something how it

would land with her, and then how to read her behavior, whereas I could certainly read dissent through some of their sounds and movements she would make. So I wanted to be more, well to bring out bring the horizons much clearer, not make claims I couldn't substantiate, "well she's consented to this". I couldn't say that, I didn't feel. What I did establish quite early as she was - fortunately for me and her I mean she seemed to like to be around me and she liked the attention. But she didn't give me permission to film with the camera on the first meeting. So she was happy with me there and we had fun in her front room and Mum was there. Then when I saw her, gestured towards the camera invited her to look at the camera she wasn't interested. Then I would make as we got to know each other more specific requests, but that first meeting it she didn't allow the camera. From then on she almost grew to sort of court the camera, or you know, want the attention which was obviously great news for me as I was shooting, I was a cameraman as well as the director. It's hard working with a subject who doesn't want to be filmed and fortunately I didn't have to go through that, and that may that may have something to do with the work of Kate Adams and the preparation that we did.

(AC)

I think there's a very basic sense in which when we know we are being filmed, we know it is a form of recognition, of valuing us as individuals, and perhaps as an element of that because one of the things that did strike me - and I don't know if this was just an artifact of the context - but there were quite a number of examples in what you filmed where Justine seemed to be on her own in a space slightly isolated away from others ,who were all talking around her and I wondered to what extent there was this element of - does she? you know, I know it's very hard. We can't ask her very easily, clearly understanding, you know, how she's feeling about it. But being alone, one of the things that she experiences as a common factor...

(PR)

As people who have probably know better than I do, the dynamics for each individual person is really different, and you can't sort of generalize, and say for Justine what I came to understand and I think you see it in the imagery, is that she really wants connection. But her way of having connection is to.. So if we were in this space you probably want to hang around by the threshold of a door, at a bit of the distance. But she does she doesn't want to be alone a lot of the time, but she doesn't want to be touched, and that's something that. I don't know how many people here are either parents or involved with children. You know as a parent, you want, you naturally want to hold your child, and you want to be close to your child in that way, and the family have learned that they must not do that because she will not allow that. When we did a screening and Q&A with her sister Jordan, who spoke so beautifully about Justine having made her the woman that she is. She said the best they can do sometimes is steal a cuddle after bath time and you know, there has to be respected. Also for a parent to learn to let go of that almost instinctual thing of holding a child, or a young person, that's a really big thing and you see it in their body language and I think that's what you're picking up, quite rightly Anna, is that she is almost like her brother insisted it's almost like she's in a bubble. And there's the truth to that because she won't allow proximity beyond a certain point. In fact I've found, she, I was quite flattered by this, because she came towards me quite a lot. I felt...

(AC)

...and that's a positive action.

(PR)

And she was sort of choosing, almost to touch, and that was, I felt like that was a real sort of gift. I read it at times as a gift of her acceptance and interest.

(Audience question, off-mic. indistinct) ... how can you know??

(PR)

Yes that's a great question. I wrote a part; I wrote a book chapter that Kate asked me to write about this in around this work. We called it the art of not knowing, the art of not knowing, because I think the truth is we can't fully know how it lands with Justine. I mean we showed it to her. I showed it to her and the family. and the family were really surprised by some of what they saw in Justine's behavior. And that really interested me because Mum at one point - "Justine's going do this" - and she didn't, "I didn't know that Justine would do that". I think there was a moment Justine was moving towards another child when she was leaving the supermarket and seeking to connect, which was a failed attempt, because the sounds she was making actually drove the other child away. Then there's the beauty of her ability to connect when she opens the gate for one of the other children coming into the playground, and that kind of range of behavior was something that surprised some of the, you know, the closest people in her life. I thought that was super interesting, because sometimes we think we know the other. They are our mum or dad or brother or sister, or work or whatever it is, and actually do we. Do we really know? And that's something that I thought that *Justine* in a way, in the process of making this film, was a real kind of learning. Teaching me something about assumptions about another, and just because Justine doesn't speak I can't check things out linguistically in the way I normally would, so I have to work on the basis of trying to create this opportunity to connect and see what comes back. But I can't I don't feel I can make the claim that she's given her consent in the way we would normally understand it. I can say I'm confident that she assented to what we did and she didn't object visibly when we showed the film. but when we showed the rough cut. the family would told me how they wanted the film to be. In fact we introduced all the talking heads and interviews at the end. My original idea was the whole thing would be a cinéma vérité, you know, something observed and I wasn't going to allow anybody speaking on Justine's behalf, including, you know, there's the key and wonderful people. It was going to be her experience, but the family - and I think they were right on balance - were saying, we want to speak and be part of the point of the film. The timing of making the film was its first showing, was the case assessment for Justine, and you'll know better than me that the moment that you turn eighteen in the current care system, that is D-day for a lot of families. And what happens to the funding package, what happens to future arrangement, well you know all that better I won't go into that. And what was happening and what's happening today all over the country, is that these judgments are being made based on a little report made by an overstretched social worker. And those people are under pressure, you know, and how do you how can you really understand the lived textured experience, where you know, no two people in this room are going to have exactly the same energy or deal with exactly the same issues. So how can the state, as it were, deal with individuals if it's not willing to use the tools that we've got now through social media through film and so on to try and give a portrait of somebody. And then we can start to respond, and so for me the film was very much about trying to respond to what that family needed then. So so when they said to me, we want to speak, and we want to say - I was sort of handing over editorial control to the degree, and not fully, because in the end, you know it's a directed film and I made a lot of the key judgments but hopefully with their well. Yes

there has been, with the family's agreement, and in Justine's case, I'd say it's with her assent, but I can't for the reasons described, it'd be too ambitious to call it consent. I think that would be too arrogant in a way.

(Audience question, off-mic. indistinct) ...

(PR)

Thank you, thank you very much. I really appreciate that.

(Audience question, off-mic. indistinct) ...instead of awareness raising we're talking about educating...As a Course Leader how do you shape narratives.. in documentary.

(PR)

There's such a massive job of education to be done here, isn't there, and on many fronts, and so the question here is "what am i doing?".

I guess it's just to a small degree reduced my ignorance a bit, and on the basis of that, I can be a bit more confident in helping others to this place. Beyond, alongside these films, I also write and in fact there's a chapter I think I mentioned it, *The Art of Not Knowing*, and so I publish what hopefully will be useful educational materials to help others explore this territory. We've got such a long way to go, and also these issues fractured differently in different communities. With another hat on I'm a trustee for a children's education project that works with so called "untouchable" children that's within the Indian system. There's this horror of the caste system. and if you're not in the caste system, you are so called "untouchable". We do a lot of girls' education stuff, for girls who live on rubbish dumps in India, with families, that was particularly for the girls. I was trying to do some stuff around disability, and being told there aren't any disabled people, there aren't any. How about that? There aren't any. So we went to work in some village and then there was a UN Day of Disability. It happened to coincide with that and, I don't know how to put this, children were brought out of huts and dwelling places - they were hidden. These children haven't seen the daylight. There is so much stigma, in you know in some parts of, in that case, the Asian community. Well in particular parts of Central India, there's so much stigma, and it's connected to all sorts of beliefs around karma and what disability means, and so on. So in different cultural organizations - I'm not generalizing. There's fantastic work being done in Asian communities in different places, and I'm well aware of that, but I think wherever we come from we need to be confident enough to name the horrors within our own communities. We need to say this isn't acceptable.

(Audience question, off-mic. indistinct).. having awareness doesn't make me go up and speak to them and engage...

(PR)

Well it depends on what kind of awareness... You could say David Cameron is aware of disability because of the tragedy that he suffered with the loss of his child. You would think that that awareness, it's more than awareness, that's a lived experience would mean that they would at least be more direct lines of communication between the hardest hit communities, and what's happening to services, of funding, and so on. You'd think that actually we've got a Prime Minister who's got some lived experiences, so I'm with you about it. It does make me wonder whether there's got to be more

effective ways to lobby these people. How do you reach this, and there's got to be ways to do it.

(Audience question, off-mic. indistinct)..

From a couple of comments that have been made, and the comment that the sister made before... Very often the parents are so over protective, that it's stopped development and that's quite scary. To get back to your actual film, there were two parts to that film that were really strong for me. One was you cut the sound down and music disappeared, it was almost bringing out the isolation. The other one was when you actually switch the screen on. They really did make me think. By the end of the film I was almost in tears. It was lovely to see the rabbits, right at the end. Thank you for that, it really did make a difference just to get a few seconds of that something that took your mind off... it took it away you could think about what was going on...Parents were very overprotective...fine balance.

(PR)

People need help. I mean it could be such an isolating experience. Well you know all of this very well, and I guess, if there was an ambition for this work, it would just be to help a broader mix of people cross those bridges. To be able to be for the carers, to be supported in more of a way, so it doesn't just fall to a handful of people who bear the intensity of what needs to be borne, and also you know to be able to celebrate what there is to celebrate... of which there's a lot. I've learned a lot from Justine. I value my time with her. By coming here, any money though would have gone to the production company, that's going to her family, that's so... I feel brilliant, I feel really good about that, she's got into horse riding. Horse riding is really expensive. It means she can have a lesson or two. There's something practical and that gives mum and dad, you know, a few hours break when they need it. Little things but little things mean a lot.

(AC)

I think one of the things that I can take away very positively from the film is this this is not a young woman who cannot communicate. On the surface our initial introduction to her through the synopsis in some ways, gives us the idea that she cannot communicate, but this is a young woman who can communicate and she is using her voice to be expressive, and there's a lot that comes through there. But thinking about both what you were saying about the hidden children of India but also what Andy was saying that overprotective parents I can't help but contrast what you've done with *Justine* against a short film that was made for the Midlands news in the early 1970s, which we showed at the Doc Media Fest last year, where there was a young woman who was being described as in inverted commas "severely disabled". It was basically about all the technology that she needs in order to simply maintain life. Her mother was the one who was standing there - dressed like Maggie Thatcher on a bad day - who was being very authoritative. Who was talking about her as if she had no participation in her own life, except when she'd say things like, "Oh she likes listening to ... to improving programs." The girl, the young woman rather, in in that film, she was completely paralyzed except for, I think it was her big toe, and they fixed up everything so she could change the channels on the radio with a big toe. But the young woman wasn't seen in the whole film, only her toe was seen, so...

(PR)

Sorry you just remind me of a word that sums this up for me which is "behalfism". "Behalfism", that people speak on other people's behalf. And there's a definition of poverty which is not being able to tell your own story, and I think wherever possible if these, in this storytelling, the narratives, the experience can be led by those people that's that a prize working towards. And I've been told for a long time and through what I'd seen the absence of, what I seen, there was a sense that if someone couldn't talk they couldn't, as it were, tell their story. I think Justine tells us a lot, by the gift of allowing a certain kind of presence and by enabling and observation.

(AC)

The very fact that her family learned something from your film enabled her to communicate with them, enabled her to communicate with them in, it in a different way and for them to actually ask questions of their own responses.

(PR)

I interrupted you Anna were you about to make another (point) before I said this behalfism, or something.

(AC)

No, no. I'm going to draw to a close so that we can have a full hour for lunch and then be back on schedule at two o'clock. I'd like to thank Pratap again very much and the film will be re-shown own later, and as you know Pratap is not going to be here, unfortunately he's got to go and teach.

(PR)

I will stay over lunchtime. Really interesting to take our conversations further, and if anybody had any other comments, that there wasn't time and also criticisms. I don't think this is a complete work. I think this is the beginning, the mere beginning or the development of something and that always means that it can go somewhere even better, so feel free. You don't have to like this work; I just appreciate the engagement with it. Okay. Thank you very much.