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Kaiser Family Foundation Tutorial Ethical Issues July 21, 2008

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RENATA SIMONE: I think the most common ethical dilemma is about protecting the source. We want to tell people stories and we want to give a full accounting of what is happening to them. But, at the same time, AIDS is tremendously stigmatized as a disease. And people react very harshly. So, when we report the story, I think the first thing we have to pay attention to on a daily basis, and it really is an ethical problem, is to do no harm like in biomedical ethics. First, do not harm.

CZERNE REID: A big problem is just getting people to go on record. They will tell you their stories but they do not want their names in the paper because they do not want their neighbors to see and they do not want anyone to know. So, that has been a big problem. And I thought, okay, covering it as long as I have now for more than a year, that people would be more willing to be on the record. But, I suppose the reality is what it is and they just do not want anyone to know.

JACKIE JUDD: And is it sometimes a question in your own mind, how far to push? It is in your interest as a reporter to get them to agree to be identified. It may not be in their interest, clearly.

JOHN DONNELLY: It sometimes is not in their interest and sometimes you leave a discussion thinking, if I put that in the story, that could potentially harm them. So, if I have a

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question about that, I do not put that in the story. I think you have to have your own code of personal ethics of how to deal with that. In the decision not to be public, sometimes it is very clear. They have very good reasons for not doing it. I then though, will explain why I am doing this story, what the audience is, who would see the story.

JEN KATES: The story has to get out there for society to really understand the complexities of tackling HIV. But, to do so, there is a lot of things reporters can do. It is really interacting with people that they are talking to, being very clear up front what the story is going to be about, what the perimeters are. If there is a camera person involved, really understanding what the community that they are working in, what the individual that they are working with is comfortable with and respecting that.

Because if that boundary is crossed, it not only will cut off further opportunities for stories in the future, but the serious implications that someone could face in their community really should be the driving force here.

RENATA SIMONE: In the effort to get the story, we forget that these are real people. When we turn the camera off or we close our notebooks and we leave, they have to live the rest of their lives. So, yes, there have been situations where I have convinced someone, only when I knew it was absolutely going to be safe for them and that, by them telling the story,

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they would really help other people.

JACKIE JUDD: If someone ultimately chooses not to want to be identified in the piece that you are writing, how do you shield their identity and yet still report on their experiences?

JOHN DONNELLY: That is really a very difficult situation and I try to learn from them. So, I will talk to them about whatever the topic that I am covering and spend time understanding what it is so I have a further depth of understanding. But, I generally do not use pseudonyms or use a full experience of someone who is not willing to come public. I then will use that information to go try to find someone who will go public.

So, if it is an extreme situation, and there have been an extreme situation in the history of AIDS is people who have been infected through various means, through blood transfusions or hemophilia, children, where obviously their identities have to be protected, especially has been the case in the United States quite a bit.

RENATA SIMONE: I just did an interview with a woman in shadow, one of the very few shadow interviews I have ever done and it was not because this woman was afraid for herself, it was for her daughter. And her daughter knows and her daughter is fine and very supportive. But, it was maybe not so much her daughter now when her daughter is 14, but it is when her

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daughter is older, protecting her in that way and I honored it.

BRENDA WILSON: So, the idea that people do not want to be identified is a very difficult question for reports because editors are very reluctant. They do not like printing stories about people who do not want their names used. And I am very sympathetic to the patient however.

I believe that they have a right to their privacy and I almost understand that until we get to the point where HIV and AIDS is accepted, generally, that they have a right to it and it has to do with the patient's awareness of what their rights are and that is a lot of people in particularly developing countries, where they are dependent upon the health facilities where they would be going for assistance, do not know that they have a right to tell you that I do not want to talk to you.

Because they are seeking help, the health facility is thinking funding perhaps and so your question is, I tend to err on the side of, they have a right to know and I tell them, you have a right to tell me that you do not want your name used, you do not want to talk to me. Know is has nothing to do, it is almost like informed consent which is an issue that people who are doing research understand but I feel as a journalist, I also have that responsibility as well.

JACKIE JUDD: How important is the investment of time on your part in the people whose story you want to tell, as opposed to barging into a room and saying we want to interview

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you, let us do it.

RENATA SIMONE: I have seen both. They call it parachute journalism, as you know, where you sort of drop in from nowhere and the journalist sticks a microphone in your face and says, how do you feel about that? Is it not horrible? The investment of time is the most important thing to me. There are two parts of it; the time before when you do your homework, when you find out as much as you can about the culture in which the person is living, what the norms are around these kinds of transmissible diseases, you just do as much homework.

Now, with the internet, it is much, much easier than it used to be. You can find out just about anything you want to know. And then there is the investment of time with the person and there is no substitute for face-to-face. Unfortunately, budgets are so tight that you have shortened time for your homework or your pre-research and shortened time for work on the ground.

Very often, you have to do the research and then do the interview within days of each other. So, you do not have time to really work on those relationships. And in that case, what I do is work on relationships long-distance with people who are trusted in the community. So, maybe it is the head of the AIDS Service Organization or it is the Principle of the school or whoever the kind of opinion leaders are of that area.

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CZERNE REID: I go to meetings, I got the state conference, I go hang around with people in the community organizations. So, I would start seeing people in 10 different places and so everyone would get to know me and then they would realize, okay, if there is an HIV/AIDS meeting in the Health Department and we are to be there or if there is a Task Force meeting, I am going to be there and then I would write stories at particular times when different developments came up and so they started then began to expect that I would do it. But, I was doing it anyway.

JACKIE JUDD: Have you ever acted as a kind of go-between between a reporter and someone who is HIV positive and they have some hesitancy about talking to that reporter?

JEN KATES: Right. That is a very good question. I would not just put two people together, the subject and a reporter if I did not feel like that reporter, after I have talked to them, was sensitive to the issues at hand. So, I would want to discuss with a reporter, do they understand?

First of all, what is their motivation for the story? What are they trying to do? Who else are they talking to for that story? Do they understand the implications that their reporting could have, good and bad, for an individual, for a community, for a family? You can get a pretty good sense, by talking to someone, if they understand those things or if they are willing to be educated about those things so that they can

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proceed.

JOHN DONNELLY: In many places I have also found that I can keep going and keep going and find someone who will go public and will understand what it means to go public. So, I think it is very important in the long view, to erase stigma. And one way of erasing stigma is to have as many people go public about the disease as they possibly can find.

When someone says that they are willing to go public, sometimes I go much further than to just explaining where it is going to go. I say this is how I am going to use the information that you gave me and these are some of the things you should think about now that information can travel across the world on the Web. That means that even if you are in a remote area, the Congo, there is an internet café down the street and there is the chance that someone in that café could see a story about you, kind of a remote chance.

But, you want to make sure that when the person talks about it, that they feel comfortable that in their own neighborhood, in their church or in their mosque that their neighbors could know that they are positive. And that is generally people in Africa have been more open in revealing their status to a Western reporter because they think that they are still protected by it. So, it has been my job to talk to them more and more about whether that protection really exists for them.

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BRENDA WILSON: As we move to online media, you cannot say that something that you are covering for perhaps being transmitted in the U.S. that that is where it is only going to be seen or heard. If it is about someplace in Zambia, the Zambia media will pick it up and use it as well and it goes global. So, even if it is some person in a village somewhere, you would be surprised. They know about your work.

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