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## Interview with Tricia Regan, Director of Autism: The Musical

By: [Kathleen J. King \(View Profile\)](#)

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**Q: What inspired you to make this film?**

**A:** Autism first came to my attention in a psychology course in high school ... then in my first semester in college, I took abnormal psychology. In that class, someone came to speak to us who ran a clinic at a university for autistic kids. I was so intrigued from the first time I saw the word, so I did an internship at the clinic. It was pretty devastating. In the 80s ... it seemed that once people reached a certain age, they were just put into institutions. I was put with older kids who'd been in institutions all their lives ... I was teaching them how to put a fork, knife, and spoon in a bag so someday they would be able to work at a factory.

It was hard to communicate with them, but at the same time, I had the sense that there was something more. Years later, a good friend of mine and the executive producer on this movie [Janet Grillo] had a child who was diagnosed with autism. This brought me back to thinking about the issue. Then she was approached by some people who wanted to do a documentary on the film ... just as a favor to her I started talking with them ...

But I told her, "Look, I would rather go to a root canal appointment than show up for an hour and a half movie about autism ... it's painful as hell! We need to come up with something where autism is not the subject, but the obstacle. So it's about people facing autism, not about people being *engulfed* by autism. I suggested a group of kids putting on a play. It turns out they knew a woman [Elaine, director of the Miracle Project, in film] who was working with kids with autism on plays ...

**Q: I was struck at how well adjusted and happy these kids were. What's your take on that?**

**A:** We tried to set up a dichotomy where there's life outside the Miracle Project ... and then you come back to the Miracle Project and there's a sense of calm and acceptance ... then you go back into the real world

where marriages are breaking up, kids aren't getting into schools—and I think that was true of the experience ...

Some people have said, “Well, this is a really high functioning group of kids” ... but the group of kids is self selecting. These are parents who took their autistic children and signed them up for a musical theater program. Number one, you have a group of kids whose parents are very invested in them to begin with and invested in making their lives happy. Number two, you have a group of kids who are drawn to the stage ... so they're in an environment that makes them happy ... They *are* pretty happy, but they face some serious challenges and are facing them very courageously.

**Q: Of all the children in the film, whom did you most connect with?**

**A:** I loved them all. And there were six others we spent a lot of time filming, but we had to narrow it down. They're all great spirits. That was really important to me in this movie: to show the kids. They're human beings, they're kids. Fall in love with them!

They're here and they're not going away and right behind them is a whole other generation coming along. This is a reality we have to face. Since the time I began making the movie and today, it's [autism] increased from 1 in 166 to 1 in 150, so it's not getting any better. Yes, it's true we know more about it and there's more diagnosis. But anyone I talk to who works with autistic kids (teachers, pediatricians)—and who has worked with kids more than twenty or thirty years—says there's a marked increase with children with neurological issues ... Something has gone horribly awry.

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And not only do we need to figure out what that is and correct it, we need to work with this part of our population and find a place for them. All these kids have something to offer, but they're not going to be able to get up and go to work each day, ride the subway, pay their bills, they're going to need some level of assistance ... Can we afford that? Can a society provide that? I don't know.

There is new legislation that [Senator Hillary] Clinton introduced recently called “Expanding the Promise” for individuals with autism, a well-written piece of legislation ... I would really like, if this film rolls out and has a theatrical life, to somehow use it to push forward legislation and get people behind this. Because it looks at what the needs of the kids are now, and makes that available to everyone whether you live in Kalamazoo or Los Angeles ... It's a very comprehensive bill ... As someone who's been pondering these issues for more than two years, I couldn't have written it better ...

**Q: Did you ever consider interviewing experts?**

**A:** Yes. When we started making this film, we were going to use experts. But then I felt I didn't want to date this film. I didn't want to spend too much time on one theory that in two years might evaporate ...

**Q: What did you learn about autism that you didn't know before making the film?**

**A:** I learned that we're all a little autistic. It's made me so much more compassionate with myself and others ... and much more understanding of the ways our senses are interpreted and interact with our cognitive abilities. It's so different from person to person.

I realized I have this immense sensitivity to lighting. Florescent lights, overhead lights, I can't stand. I will come into a room and change all the lights and I won't be comfortable until I do ... I just figured everyone else did. And so it made me irritated with others, and it made others irritated with me: “Why is she making such a big deal of this?” And also understanding the kids ... why aren't they [autistic kids] paying attention to me right now? Well, because the sounds may be over stimulating to them. That is, autistic kids' neurological

systems can be so compromised that they just cannot bare the stimulation of too much noise. When you're with autistic kids, you can't oversee these things, because they're [the kids] not close enough to normal. They're so constrained that they literally can't function with certain noises ...

For example: If they heard *that* noise [referring to the loud hiss of the cappuccino machine in the café where we're sitting] they might scream and run out of the room ... *we* might inside feel like doing that, but we don't ... [But for some autistic children], it would feel like someone was sticking a needle into their ears—and there's nothing we can do to dissuade them.

If you want to communicate with an autistic child, it's got to be on their terms—because their terms are so specific and they can only deal with you if certain things are right for them ... it's a lesson in compassion and humility.

**Q: Do mothers take a bigger role in raising autistic children than fathers?**

**A:** I think what often happens (and every family operates differently) is a reversion to more traditional roles because a child needs such hands-on attention, because somebody needs to learn everything there is about this disorder and every kind of treatment there is (because there's no set treatment) ... so one parent has to become obsessed with that child and the other parent has to go out and make money to keep this going. From my sample group, it broke down along sex lines ... That said, this is an incredibly dedicated group of fathers, too, who love their children and who do everything they can.

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I think it's very frightening to have an autistic child. This particular generation of parents in my movie grew up in the fifties and sixties when most moms stayed home with the kids and most dads worked. That was the norm. So in a place of fear we revert to what is the most familiar ... It may be different for future generations.

**Q: What surprised you about the kids?**

**A:** For me, autism is so fascinating, the varying levels of functionality. Elaine [director of the Miracle Project in the film] says it's like swiss cheese: these weird holes of low function and these places of super high function. One character in the film, Lexi, has a hard time putting an original sentence together and yet she's driving home with her mom one day, and they'd just spent time with her friend's family ... and she says, "And then there's Bradley. Bradley is the dadly!" This was an overly original, *really funny* thing to say, with amazing delivery! Where does this come from? That's the thing that is endlessly perplexing ... inside all these kids, there's an incredibly high functioning human being ... It's particularly challenging for the parents who have a real need to know their children ...

**Q: How did you get your start in filmmaking?**

**A:** Growing up, I never thought of being a filmmaker as a possibility in my wildest dreams. I grew up in the 70s. There were not women filmmakers and being from Canarsie, Brooklyn, I had never met a filmmaker ... I was going to be a lawyer ... but my last semester in college, I took a still photography class. Now I'd been begging my parents for a camera since I was five years old! I was fascinated with photography. I wanted a Mickey Mouse camera! My mother kept buying me drawing supplies ... I'd say "I want to take pictures!" So, whenever I could, I'd grab the family camera ...

Later, I spent days in the darkroom ... I got into a graduate program at NYU that was a joint program with the International Center of Photography ... Later, I reached a level in my photography when I didn't want to go further. It wasn't enough for me. I took a video class ... suddenly it was movement, sound, words, music, and story ... Based on my work, I was offered a fellowship in a TV studio at NYU. That's where I learned the physicality of production ... but I was never really taught how to make documentary films.

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When I finished at NYU, I was approached to do a film about Northern Ireland [*A Leap of Faith*, premiered at Sundance in 1996] and I latched on to that ... I worked in TV after that (it's hard to make a living as a doc filmmaker) ... I've done a lot of reality shows ... and then I reached a point again where I just made a decision to make docs ...

**Q: Who were your role models in the film world?**

**A:** It was very hard coming from a generation where there weren't a lot of women role models for me (or for any of the people around me) to understand how to be in a position of leadership ... as a woman working with a crew of men who were older than me, with more experience, there was some serious cutting of teeth ... In order to succeed, I had to overcome this need to be liked. I wasn't helping anybody if they liked me. I was helping them if they respected me. Sometimes getting them to respect you meant getting them to do what you wanted when they didn't want to ... I think it might be easier for the next generation. But still, if you look around, there are many, many more male directors than female. And I don't think it's because the talent is disproportionately in men; it's the confidence and leadership ...

**Q: What would you say to women interested in becoming filmmakers?**

**A:** The strongest asset you can have, more so than talent or contacts, is faith in yourself. I've seen a lot of marginally talented people go very far—but it's because they have the faith in their ability to tell a story that others will want to hear and they firmly believe they have a right to do so.

I would say that if there's anything else you want to do, do that thing, because filmmaking is not easy! You will give it up before you make it, if there's anything else you *can* do. I really believe that. Because I've tried to give it up! But I couldn't think of any other scenario that I could live with! I think it's the same with writers. The people who remain writers are the ones that can't do anything else ... it's a calling ...

**Q: What's the most difficult part of documentary filmmaking?**

**A:** There's a certain uneasiness about telling real people's lives. It's an immense responsibility. These are real people ... they've taken a great leap of faith in putting their trust in you ... you have to find that way of telling the truth which is not going to do harm. It handcuffs you; I don't sit that easily with it, because not everyone wants to know the truth about themselves, nor do they want everyone else to know. I know that starting out. And they don't.

I think everyone has a different relationship with the truth. There are those who are in love with it—I happen to be one of them—who put it all right out there, no shame. The truth can't hurt them. Then there are other people who live in a world of their own creation and have a fear of the truth.

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