Rick Guidotti

>> LOWE: Hi, I'm Chantall Lowe from INCLUDEnyc, and I'm pleased to start this episode of "Disability, Inc." with my good friend, Rick Guidotti.

>> GUIDOTTI: Hey!

[LAUGHTER]

>> LOWE: Hey, Rick. Rick Guidotti is an award-winning photographer, and has spent the past 25 years collaborating internationally with non-profit organizations, hospitals, medical schools, educational institutions, museums, galleries, advocacy groups, and communities to affect a sea change in societal attitudes towards individuals living with genetic, physical, behavioral, or intellectual difference.

His work has been published in newspapers, magazines, and journals as diverse as Elle, GQ, People, the American Journal of Medical Genetics, The Lancet, Spirituality and Health, the Washington Post, Atlantic Monthly, and Life Magazine. Wow, Rick, that's a mouthful.

Rick is also the founder and director of Positive Exposure, and non-profit organization that promotes a more inclusive world through award-winning photography, film, and educational programs. Positive Exposure has significantly impacted the field of human rights, mental health, medicine, and education by providing new opportunities to see each individual as a human being. Thank you so much for joining us today. Can you tell us more about Positive Exposure?

>> GUIDOTTI: Sure, I can talk about my favorite topic. I can talk about it forever. So this year marks the 25th year -- now, I was a fashion photographer here in New York City. I worked here. I was also living in Milan and Paris, working for all these great clients and great models. I was always told who was beautiful, though, and it was really frustrating, because I refused to see beauty just on covers of magazines. I see beauty absolutely everywhere.

So it was 25 years this coming October that I spotted a kid waiting for a bus at the corner of 20th Street and Park Avenue, across the street from my photography studio. She was stunning. This kid had never been included in the beauty standard. What was so striking about her was she had white, white hair, pale skin -- she had a condition called albinism. Albino is the common term. This kid was stunning, yet never had I met a model who looked like her. Never was she ever included in the very narrow parameters of the beauty standard.

And I was just so blown away by how beautiful she was, and I was also so aware of the narrow parameters of the beauty standard that only allowed certain beauty in. And as an artist, I thought it was my responsibility to create a space to represent beauty in its full color and its sound and its vibration and its smells and its bright, flashing lights. That started Positive Exposure, and that really is the beginning, 25 years ago.

I've taken it from there -- from spotting this kid to finding really negative images in medical textbooks representing albinism and other genetic conditions, which just so kind of blew me -- it just knocked me off my feet. Because this kid was gorgeous, yet the representation in medical textbooks, in medical education, was predominantly negative.

And it wasn't just kids with albinism. It was kids with all kinds of diagnoses, and they were all just depicted as diseases or specimens. Always had like a black bar across their eyes. Usually naked up against a wall in a doctor's office. And I thought, something has got to change here. This is about albinism, but there's a universal message here. This is about representing beauty, and celebrating human diversity, and creating an opportunity for people to see beyond disease, beyond diagnoses, to the beauty and the humanity that we share.

So that's really how Positive Exposure started. First, the first series of images around kids with albinism was a cover story in Life Magazine called "Redefining Beauty." Showed albinism in a five-page spread. Lots of accolades for it, lots of awards for it, which was really fantastic to get these awards. But one of the awards that I received for this piece was from The

Genetic Alliance, which is a coalition of all of the genetic support groups, and they presented me with the Art of Reporting Award.

And as I received the Art of Reporting Award for the Life Magazine piece was a great honor. It was really cool. The director at the time said, “I'm looking at all these beautiful images of albinism, but there's really a universal message here. This isn't just about albinism. This is about all differences. And would you come to another one of our family conferences, or advocacy groups, like the albinism support group, NOA, that represents other genetic conditions, and celebrate their differences?” And I thought, fantastic, I would love that.

And that started this whole new -- it really kind of gave it legs and it really put us on the trajectory to really kind of change the way medical information is presented to health care providers in training. Because at that point, they were using these images of kids naked up against the wall in doctor's offices, presenting Marfan's syndrome, chromosome 18 anomaly, Moebius syndrome -- there were all these images lacking humanity.

And as an artist, I found it so easy to add that beauty back into those images. And we learn better that way. I mean, I go to family conferences and I go to medical schools right now, because I can actually pronounce arthrogryposis multiplex congenita. Not because I want to spell it or not that I studied it in a medical textbook, but I went to these conferences.

So I bring med students with me now to go to these conferences, and I shove them in day care and I lock the door on them. I check back in on them, and they always have gum in their hair, but they're going to be better doctors, because they met these kids not in crisis. They met these kids not looking like those specimens, and they met these kids not in the clinical environment.

>> LOWE: Talk to me about the tag line that Positive Exposure has around "Change how you see, see how you change," because what you were just discussing makes me think about that deeper. How you have reframed disability for the medical profession, or are attempting to

reframe how health professionals and doctors experience some of their patients. So if you can talk to us about that tag line.

>> GUIDOTTI: Our first goal, of course, we have a significant focus on health care and medical education. But specifically, we're looking in the broader public arena, specifically to change public perceptions of anyone that's different; anyone that's at risk of stigma or exclusion.

So the tag line, "Change how you see, see how you change" came from the very first photo shoot that I did with a young woman by the name of Christine. She was the first kid with albinism that I was starting to photograph in the beginning of this whole series. This was 25 years ago, shot in December 1997, believe it or not. This kid walked into my studio. The National Organization for Albinism was behind this project. All the support, we were so excited, and in walks beautiful Christine…

But she walks in with her shoulders hunched, head down, one-word answers, zero self-esteem, as a direct result of the bullying and the teasing and the abuse she experienced every single day in the classroom because of her difference. And it broke my heart to see this kid who had zero self-esteem just standing there. How am I going to photograph her? But just the day before, I photographed Cindy Crawford on the same set for a Revlon shoot. So I thought, you know, out of respect for this gorgeous kid, I want to photograph her like I would any supermodel.

So the fan went on, the music went on, and I literally just held up the mirror that was next to the set, and I held it up to her face. I said, “Christine, look at yourself. You're magnificent.” And this kid looked in the mirror, and she saw exactly what I saw, and she exploded, literally, with a smile that lit up New York City. Christine desperately needed to change the way she saw herself. Her community desperately needed to change the way that they saw her difference.

So that's where it came, the whole slogan came: Change how you see, see how you change. She walked into school the next day not like she normally does, with her head down, but like this, wow, because she finally -- once you're enlightened with that vision of beauty, it sustains itself. You never reverse back. You just stay like.

>> LOWE: So you awoke the supermodel in her that was always there.

>> GUIDOTTI: Always there, it was always, always, always there. We all have them inside of us, but we just need the right light.

>> LOWE: I also hear this theme of your work, or starting to hear this theme that was unravelling in your work around, dare I say, cultural activism. It makes me think of another project of yours, your FRAME Project, which is Faces Redefining the Art of Medical Education. Can you tell me more about the purpose of FRAME, and what FRAME hopes to shift?

>> GUIDOTTI: We created FRAME, because from that perfect experience of going to the arthrogryposis conference, meeting these gorgeous kids, and I just thought I needed to bring med students with me to all these advocacy organization conferences. And I go to many of them in the summer months. Bring med students with me.

But we can't bring them all with us, and each year, there's another generation of med students that we really need to enlighten. Over 50% of the medical schools in the country at the moment, which is amazing that we have another 50% to go through. But it's really important that we all get that message. A health care provider early in their training understands that it's never what you're treating, but always who you're treating. That's the message of FRAME.

FRAME, they are 8 to 12 minutes. There are films. It's an online film library. It's on our website. They're 8 to 12 minutes long. All the basic hallmark characteristics of a certain genetic condition. But as presented by somebody living with that genetic condition themselves, or their families. So placing front row and center in medical education, humanity.

The films are specific early days going towards medical students, and we still have a very wide, really heavy use in medical education, but they're also available and they're also being utilized in the broader public arena. Because after all, whatever country we're in, which continent I'm on, which culture I'm in, which language we're speaking, or how many translators I have out in the bushes in Mali and West Africa, we all have the same need, and we all share this need -- and it's a need to be seen, a need to be heard, and a need to belong.

>> LOWE: What I find most interesting about FRAME is you're not only talking about individuals with genetic conditions. You've also tackled some multilayered topics. An example that I recently saw on your website was you have a FRAME film on early-onset Alzheimer's in Down syndrome. You also have one on supported decision-making, which supported decision-making is an alternative to guardianship for individuals with intellectual disabilities, about navigating their decisions, really, in adulthood.

Why have you kind of gone that track as well? It's not just about humanizing different conditions, but it's also exploring topics within that affect --

>> GUIDOTTI: Because we're not really sitting on making those decisions that we're going to cover this topic or that topic. We sit and we listen to our community. Our community of people experience stigma, exclusion across the board. And we're there, and we say yes to everyone as often as we can, and we're getting funding to do this.

So when we speak to a community -- I just met with a whole series of health care providers who had no idea that supported decision-making was a thing. And can we at least present that? We're like, of course. So we worked that in, and we got funding for that, and then we go ahead and pursue that.

So many of the people that we photograph, and our ambassadors, we don't want to just tell the positive stories as well. We want to make sure that there's a really well-rounded network here, and we're presenting information that can be helpful. But really, by relying on the experiences of our community, and having them understand that their stories, their experiences, once shared, are so valuable, and we need to capture those.

So right now, we're working on a collection of over ten FRAME films for this next year, starting one streaming Saturday on the lack of representation of dark skin in dermatology education. So you're getting all these presentations for a variety of skin dermatological conditions, but very rarely do you see them on dark skin. So how do we recognize that? So we're working were closely, and that starts Saturday.

We’re really looking at how mental health and disability and that association are really creating that space, and looking at really trying to understand how life impacts all of us, and tell those stories. So we developed the supported decision-making, created that film, because we're listening to our community and they asked, can we do this? We need something out there. So it's a beautiful little film.

Same thing as our early-onset Alzheimer's and our aging Down syndrome community, or adult Down syndrome community. We have so many gorgeous kids, but then so many of these, and they become so independent, and families really support them, and they're out there -- and then all of a sudden, they start losing their independence, because the protein for Alzheimer's is on the 21st chromosome.

>> LOWE: I didn't realize that connection.

>> GUIDOTTI: People with Down syndrome have three chromosomes, so there's a fairly high risk or incidence of early onset. So we really want to have those conversations, and make sure that we're aware of that. And that it's nothing to be ashamed of. We're just kind of having these important conversations, sometimes difficult, but putting the information out there. And also to empower families to know that, again, their experiences are valuable, and will be valuable in future health care providers' training.

>> LOWE: Before you spoke to the fact that you are in 50% of medical schools across the U.S.,

how did you get into medical schools? How did they embrace your work? I'm assuming they embraced your work, because, of course, I'm a huge fan of Positive Exposure. But what was that entry point into that space?

>> GUIDOTTI: The entry point was -- it's a bit of a convoluted story. But the entry point was the co-founder of Positive Exposure was a doctor, Diane McLean. She was a second-year med student at Weill Cornell, and an old roommate of mine, early '80s, before I moved to Milan, before I lived in Paris, and we were really great friends. We kind of lost touch. Diane went to Columbia. She was an epidemiologist there. Worked in the children's health, and then she decided that she wanted to be more proactive in health care, so she went to med school.

During her class on genetics, they presented the "Positive Exposure Redefining Beauty" Life Magazine piece in her classroom on showing albinism. She's like, “Wait a minute, I know him!” So she called me immediately. Like, Diane! I was screaming. And I was getting ready to go to the South Pacific on a small grant to explore cultural perceptions of albinism in the South Pacific.

I found out that in Fiji, a tribe couldn't hold their territory unless they had somebody with albinism in a powerful political position. So it was important, we wanted to go and explore that. Also, in the Cook Islands, there was a beautiful legend about the first person born with albinism. And then there was also a group in New Zealand that didn't have a formed albinism support group, but they asked me to come and help them get that together.

So Diane came as an epidemiologist, first-year med student from Weill Cornell, on a grant that we received from the International Fellows Program at Weill Cornell. So she came for two months with me. We traveled around. Part of that grant was we had to present it to the second-year med students. So we did that. That was in 1999. So we just had my 23rd presentation to the med students at Weill Cornell. So some of the students we spoke to that first year are almost retired now.

[LAUGHTER]
And it's always great, because it's presenting an idea. I'm not lecturing saying, you have to think this way, you're wrong. It's just coming from a beauty perspective. We all know that there's a lot of science in medicine, but there's a lot of art and passion in medicine as well. That's really what we're doing. We want to get these health care providers in training to stay connected to their passion. Staying connected to their art. And thoroughly seeing the beauty in medicine.

>> LOWE: Wow, I'm not sure I've ever heard that there was art in medicine, but now I can see it. I'm moving along with you to that vision of seeing the art and passion in medicine.

>> GUIDOTTI: It's so there. I'm starting on several new projects. I just started a project, a FRAME, but also a photographic exhibition, on the NICU experience, the neonatal intensive care unit experience. Not just from the perspective of the families that are often in the NICU for months and months at a time, sometimes a year; and it's the community, they can't bring all the grandmothers and the uncles and the cousins to come visit, because it's the NICU. So they've got to keep it really a capsule.

So it’s that relationship with the NICU, but also telling the perspective from the staff, from the nurses, the doctors, the lactate doctors, the physical therapists, the language and speech therapists, everybody together, down to the person who scrubs the floor to make sure that these kids live in a germ-free environment, and valuing those experiences as well. We're starting it in Florida, going to do it here in New York, and then Austin, and then create an opportunity to have other photographers around the country do the same in their local NICUs, as we build this platform.

Always collaborating with other photographers, knowing that it can't just be Positive Exposure. It can't just be Rick. We've got to do this hand in hand, arm in arm, to change the way the world sees differences.

But another project that we're starting, I'm off to Berkeley in a couple of weeks, at the end of this month, is working with doctors with disabilities.

>> LOWE: Doctors with disabilities, tell me more about that.

>> GUIDOTTI: Extraordinary group. We're starting in Stanford, and there are doctors out there that have disabilities, and are ready to talk about it. They're not hiding. Yet, we're creating, because there's always this hierarchy and medical education. We've got the perspective of doctors with disabilities who are already at this level for health care providers in training to see them and their mentors.

It's going to normalize disability. It's going to bring disability out of the -- not normalize it, but it’s going to take the stigma away from it. In medical education, there is stigma in disability, and I've devoted my life to getting rid of that, eradicating that stigma, and I think this is going to be a really incredible start. So we start in Stanford, and it's going to just be amazing. Across the board, doctors stepping up, visual impairments, mental health challenges, mobility issues, it's just across the board.

A doctor that I met, her name is Dr. Nadia, she was a second-year med student in Doha in Education City when I met her. She has acromesomelic dysplasia, a very rare form of dwarfism. Amazing, gorgeous, stunning, glorious.

>> LOWE: I recall your images of Dr. Nadia. She is absolutely stunning.

>> GUIDOTTI: Dr. Nadia said to me when she was a second-year med student, “The only thing I need to be a successful physician is a stepladder.”

[LAUGHTER]

And she got the stepladder. She did her residency at Children's Hospital, Dayton, Ohio, post-doc at Baylor, now she's in D.C. Got married a year and a half ago. She just can't wait. We haven’t been able to be together because of COVID, but they're planning a trip this summer for the wedding photos. I'm so excited, very excited.

But again, it's just looking at -- it's perspective. It's changing perceptions -- and not just in the medical field, but in broader public arenas as well. Creating opportunities beyond disease, beyond diagnoses. It's our differences that unite us all, so we need to embrace those.

>> LOWE: Again, you bring me back to this thought of really inherent throughout your work the last 25 years, is this activism, this kind of throughline and thread. And I was so pleased a couple years ago when I learned of Positive Exposure opening an art gallery on Museum Mile. Tell me the significance of having your own gallery space for Positive Exposure.

>> GUIDOTTI: This has been a dream for 25 years, to have a safe space, a multimedia gallery space, performance space, where we can create and celebrate the art from our community, the art that's being created in our community, whether it's through multidisciplined art. It can be performance, poetry, painting, photography, tactile, across the board.

But creating art that also is accessible. Making sure that the art, there's a way that the art can be enjoyed by our communities that have a certain -- that are not normally able to see and experience artwork because of using certain senses. But creating art that is accessible. How do you create accessible art? What is the art of accessibility?

>> LOWE: What is the art of accessibility? I don't think you can throw that term out there without giving me a little bit more.

>> GUIDOTTI: There's a beautiful -- so many of us feel the burden of making things accessible. There's no burden there, there's a beauty in that. There's a beauty in being able to share something stunning with people that can experience it any way that they want. So that creates its own level, its own platform of art, of how do you make it accessible? And how does that become part of the actual creation of art?

And making something accessible is part of -- it's like choosing a light red or choosing a texture. It's making it accessible. It has to be part of that language. And that's really made art accessible and enjoyable. I was at a school for the blind several years back, where we just started learning and talking about how -- and it was a school for the blind, I'm talking about my photography and showing photographs. Really speaking to the students. What does it sound like? What does a smile look like to you? What does somebody in the color red look like to you? What does someone jumping on a trampoline look like to you? What does it sound like? And creating this new language, it just adds so many layers to the creation of work.

That this gallery on Museum Mile, 109th Street, that you're all welcome to, we're there all the time, just come on by. It's exactly that. It's creating opportunities to come and enjoy, experience art, to experience, and to have a place where you can come and really dream big. We're all limited by our own imaginations. This gallery is creating a safe space for us all to sit together and sit at the same table and dream as large and as big as we want to change the way the world sees differences, by doing it in collaboration and creating community.

We've hosted exhibits of so many different artists and photographers and performers and dancers, and that's just going to continue to grow. It's to have this space at 109th Street in East Harlem on Museum Mile, right across from the Africa Center, provides an opportunity, a safe space for us to gather, to be here, to have a place that we can call our own, that we can work out of, that we can try new ideas.

But we just received a grant from the New York State Council for the Arts, and the grant was to create opportunities for disabled artists and non-disabled artists to collaborate, to create artwork together, raising the visibility of our disabled artists on the stage, on the screen, and in the broader public arenas. Creating opportunities to really change the audience out. We don't need so just be showing to disabled audiences. We have "CODA" just won the Academy Award. How amazing is that?

It's a human movement, and we had better get on that boat or we're going to miss the ride. And it's to create that space downstairs -- I'm on the third floor right now of the Galleries on Three. And even during COVID, when we weren't able to bring people into the gallery, we have a courtyard that we share with the Common Pantry in New York City, right here on 109th Street, and working with an artist by the name of Marco Santini, we created a four-story mural with the word "love" in over 100 languages. It's monumental, and you must come and check that out.

>> LOWE: That's absolutely beautiful. I've personally only seen it in photographs, but I plan it seeing it in person soon. Wasn't that project also in collaboration with District 75 schools in New York City?

>> GUIDOTTI: It started off on its own. The art campaign was to fill the world with love. But the New York City Department of Education and District 75, the classrooms where students need to spend a little extra time, certain extra time that they need in the classroom environment, particular attention, we then collaborated with District 75 to create artwork on the campaign to fill in the world with love.

So we started off, first, we had an exhibition right before the pandemic, before the wall went in, on "Myself, My World." It was a city-wide, all the boroughs submitted art about telling us the world a little bit about themselves. And the artwork was magnificent. Of course, we had to shift to a virtual platform, which we did because of the pandemic.

But we kept that relationship, and we created artwork based on the wall of love. First we did luminaries with these little bags that came from around the globe, but also all throughout all the schools in New York. And then we just did another one where we have public spaces where we have students kind of creating again, fill in the world with love, what does love look like to you? Creating artwork that we installed on two schoolyard buildings on fences in East Harlem and also down in the East Village.

And then this Friday, we're installing another artwork based on another artist from District 75 -- this gorgeous artist, painter, and she did a little class with all the students and teachers and inspired their work and all that. We have over 450 pieces that we're installing in the schoolyard.

>> LOWE: All created by District 75 students?

>> GUIDOTTI: All created by District 75 students, and the work is magnificent, magnificent, and it's going to be so powerful. It's going to cover a city block this New York City. Going to be amazing, I can't wait.

>> LOWE: It sounds amazing. I hope you do share the information with us later. Again, I thank you for spending the time talking with us. But there's this very clear “change how you see, see how you change” kind of throughline throughout your work. And really the excitement, it's palpable, of how you continue to ignite these opportunities for beauty.

>> GUIDOTTI: The thing is that the beauty exists there. It exists there. We're just trained not to see it, because every day we're told what's beautiful. What is beautiful, what's acceptable. And it's like, no! I'm very sorry, I've given that up. I'm not buying into that any longer.

Every day I prove to myself that the beauty exists in full color, at full sound and vibration and motion and smell. It's all there. It exists constantly. Just training us every day to see it. It's 25 years ago, I spotted that gorgeous kid waiting for a bus. And I often think to myself, how often did I walk by that kid until I was ready to see her? She was probably there every day, and I wasn't ready to see her.

So the thing that catches me is, and what we always need to be, is be aware of that in your head -- change how you see, see how you change. Be ready for that moment where things just shift and everything becomes in technicolor and has music to it and sound and vibration. It changes it all.

One of the greatest things that I love doing so much when I'm photographing somebody -- this happens all the time. I'm photographing that gorgeous face, and they’re dancing, and they're like, yeah! That kid is shining, the white lights are on, and they're being seen in all their glory. It's amazing. Look just past his or her shoulder to his mom or dad, and they're looking, and they’re beaming even brighter, because finally, somebody sees their kid the way that they see them.

And that's kind of magnificent. That's just so incredible, to see that joy, that also becomes part. That feeds the art. That feeds the passion, and you always kind of have to have that inspiration, that language that comes in all the time. The music or the words that go along with the music. It just completes it all.

Every photographic exhibition, we've seen so many of them, we still continue to exhibit the same way. Face melted on glass, highly polished surface. So as you approach this gorgeous image of this gorgeous kid with this gorgeous smile, or giggle or energy oozing off the print, you're also aware of your own image. So it becomes instantly the language here, the message here. It's never about them; it's about us. There is no them here. There's only us. And that's what this is all about. It's kind of the impact of this is to give us all the freedom that we need to look in that mirror and celebrate our own differences.

>> LOWE: Thank you. I appreciate, as I said before, you taking the time, Rick, to chat with us here at INCLUDEnyc. We look forward to other opportunities to collaborate together. And continue on with -- I think I'm going to use this phrase -- the art of accessibility.

>> GUIDOTTI: Thanks so much.