



## **Mother and Son Activists Shared Story in *Far from the Tree***

*Emily Kingsley and son Jason are prominently featured in Andrew Solomon’s Far from the Tree, recognized by The New York Times as one of the 10 Best Books of 2012, and in the film of the same name. Far from the Tree explores family relationships when a child is significantly different from parents. Jason has Down syndrome. Emily is an Emmy Award winning writer, who was recognized by the U.S. government for her longtime work to include individuals with disabilities on Sesame Street.*

Q: Jason opens the movie version of *Far from the Tree* (directed by Rachel Dretzin) with a quote from Shakespeare’s *As You Like It*: “All the world’s a stage, and all the men and women merely players...” It’s an immediate assault on stereotypes. Tell us a little about how he has challenged limiting labels.

A: When Jason was born 44 years ago, the doctor told us that he’d never recognize us, walk or speak. We were advised to immediately place him in an institution so that I wouldn’t bond with him and to tell everyone that he hadn’t survived childbirth. My husband Charles and I ignored that advice and proceeded to immerse Jason in as many stimulating experiences as possible. He was reading at 3. At 7, he could count in 12 languages. He was a regular guest on *Sesame Street*. As a family, we spread the word that children with Down syndrome should not be “written off.” When Jason was 19, he and another young man with Down syndrome, published *Count Us In*, which excerpts their conversations with each other, family and friends.

Q: Over the years, though, your message to parents changed. Why was that?

A: As the years went by, it became obvious that, while parents were initially inspired by Jason’s accomplishments, they became frustrated—and even resentful—if their own children couldn’t replicate his progress. So I began stressing that Jason shouldn’t be used as a yardstick. I wanted the message to be that these kids should be given every opportunity to learn as much as they can, *whatever that may be*. And that if a child is living up to their personal potential, parents should be grateful and proud.

Q: In the book, you mention that Jason’s abilities actually make it tougher for him to deal with his disability—that he’s more aware of his limitations than many others with Down syndrome. Please talk about that.

A: In the early years, I thought I’d licked Down syndrome, but about the time Jason turned eight, “typical” kids began surpassing him. Jason can identify the composer and period of

the classical music he's listening to, but he can't live independently. He has trouble with social skills and nuance and needs a lot of structure. Yet most people with Down syndrome can't understand his word games or literary allusions.

He exists in a "lonely demographic," and finding friends who are like him is pretty difficult. He's smart enough to recognize many of his limitations, and that creates a lot of internal conflict. Sometimes he talks about what it would be like if he didn't have Down syndrome. Those are painful conversations.

Q: Another of your quotes from the book is "Invest in inclusion, but keep one foot firmly planted in the Down syndrome community. This is where your kid's ultimate friendships are going to come from." Please comment.

A: Yes, the film also addresses that subject. It deals with Jack, who has autism and, despite being a straight A student who follows the stock market in his spare time, is happiest with the "Real Boys," buddies who have autism. Loini, who has dwarfism, is thrilled when she attends her first Little People of America convention. And Jason's best friends are Raymond and Yaniv, who also have Down syndrome and share a home with him.

There are such limited social opportunities for people with special needs. Jason has an obsession with Elsa, the animated character in Disney's *Frozen*. He knows she's not real but, as he says, "She's beautiful, perfect and can't break my heart."

Q: This wasn't Jason's first time on film. He was a frequent guest on *Sesame Street* and appeared in the tv series *Touched by an Angel* and *The Fall Guy*. There's lots of controversy about having actors without disabilities portray characters in films who have disabilities. Is it getting any easier for individuals with disabilities to find work in film or onstage?

A: There are still very few opportunities in the performing arts for people with disabilities. In most cases, it makes no sense to put an able bodied actor in a wheelchair. The result goes beyond limiting the career potential of actors with disabilities. The audience is cheated of role models.

I belong to a couple of organizations that are advocating change to the status quo. [The Alliance for Inclusion in the Arts](#) works to encourage more accurate portrayals of individuals with disabilities and to increase their participation in the arts. [Changing the Face of Beauty](#) is committed to increasing their involvement in advertising and fashion.

Q: What do you hope that readers and viewers will take away from Jason's story?

A: That this is a complicated journey that's never over. As a parent you're on a tightrope, suspended between boosting their ego and not fostering unrealistic hopes. It's our job to

appreciate, encourage and celebrate them for who they are, as they are. Ultimately, I simply want Jason to be happy and to come to some peace with himself.

Q: How would you assess the progress that's been made towards improving opportunities, in general, for people with disabilities?

A: I think there's certainly more acceptance. At least in the urban areas that I'm familiar with, they're learning in more inclusive settings and taking part in the mainstream community. While there's a high unemployment rate in the disability community, there have been strides there, as well.

One area about which I have mixed feelings involves medical research which I sometimes think has the goal of entirely eliminating certain disability groups. In the film, Leah, who is pregnant and has dwarfism, expresses her hope that her child will be a "little person." "I don't think of myself as someone who needs to be fixed," she says.

I'm pro-choice, but by that, I mean "informed" choice, not choice that's based on fear and stereotypes. I would hope that prospective parents, faced with the possibility of having a child with Down syndrome would understand the possibilities—as well as the challenges—of bringing them into their heart. *Far from the Tree* is about accepting people the way they are. I encourage readers to check their local listings for scheduled showings.

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