

## Allan Goldstein and Liz Sargent with Jean Mizutani

>> MIZUTANI: Hello, everyone, and welcome to “Disability, Inc.,” INCLUDEnyc’s podcast series. My name is Jean Mizutani, coming to you from INCLUDEnyc’s offices in New York City. Today, I have the pleasure of being joined by Allan Goldstein and Liz Sargent. I was fortunate to meet Liz and Allan earlier this year when they participated in a panel titled, “Disability and the Family,” which focused on the experiences of siblings of people with disabilities.

These siblings face unique challenges, such as the awareness that they may become long-term caregivers or guardians, and that they may harbor resentment toward their disabled sibling or parents. Yet these very experiences seem to stimulate self-awareness and artistic expression. In today’s conversation, we will explore the sibling experience through writing and film. And I’m so excited that Allan and Liz are joining us. Welcome, Allan and Liz.

>> GOLDSTEIN: Hello.

>> SARGENT: Hi, thanks for having us.

>> MIZUTANI: First, a few words of introduction. Allan Goldstein is the author of the new memoir “Fred and Me: A Willowbrook Survivor Story.” He has published numerous essays which explore personal experiences and the social barriers that impede an inclusive society.

Liz Sargent has an extensive background in dance, theater, and film, which informs how she tells her stories. She is one of 12 children, and in her work often draws upon her experiences of having siblings with disabilities. Liz is currently working on a long-form

documentary that explores not only who will care for their parents as they get older, but also who will inherit the responsibility for the siblings who cannot care for themselves.

So what a pleasure having you on. But we would not be here at all if not for Liz's sister Anna and Allan's brother, Fred. Liz, can you please kick us off by introducing us to your sister and siblings?

>> SARGENT: I'd love to. So I have a pretty large family. My parents had four kids, and they adopted eight. Six of the adopted kids are from Korea, during a time when there was a sort of a boom of Korean adoptions. We had a -- just to paint a picture, we had a magical childhood in a big house in a safe suburb, with trips to Disney World. And there was a lot of that kind of dream of the big, fun, laughing family.

And my parents adopted six of the kids, knowing that some of them had some presumed disabilities, and many of them -- and they wanted to offer medical support in the U.S. to sort of help them work through it. And many of them have become independent. But the three youngest: one has some learning disabilities, and also struggling with borderline personality, and I'm her representative payee, sort of helping her manage her independent life.

I have another brother who struggles with seizures and some undefined disabilities. He's sort of figuring out his adult life.

And then there's Anna, who is the youngest, who was born at two pounds with a cyst on her brain. So she's sort of missing the part of her brain that has short-term memory. She is the youngest of the 12, so she's the baby. And she's fun and witty and she's physically -- she does special Olympics for tennis and bowling.

But as she's growing older, her body is sort of stiff, and she has fumbly coordination, and trouble with the daily tasks, like showering or remembering her medications, or even sort of entertaining herself. So we're in a transition right now where we're witnessing our parents having less capacity for taking care of her. And -- yeah. That's Anna.

>> MIZUTANI: A momentous moment in a family's life. Allan, tell us about Fred.

>> GOLDSTEIN: Liz's story makes our life seem like growing up in Never-Never Land. There were just two children. A third was aborted, plus the doctors thought, "Oh my, you're going to have another child with disabilities, so don't do that." So that's how the medical model screwed up our lives.

Fred is my younger brother. He's 68 years old. He wears black rectangular eyeglasses. He has a buzz cut. And he can almost shave himself. One eye is hooded, and it was hooded since birth; and I'll get into that later, about why that wasn't addressed. Fred is a charmer. Great deal of wit and humor, and quite capable of abstract thinking.

He told me this in secret, but he wants you to know that he asked his girlfriend with Down syndrome to marry him. He likes cats. Likes little children. Right now, he's in a program without walls, meaning he spends most of the week with a direct service professional in the neighborhood. So he has community acquaintances now. He recovered from COVID earlier this year. He showed a great deal of resilience. He wants you to know that he likes keys, always looking for keys.

He lives in a group home now. This is his third, which just shows that addressing his abilities has worked. He started in a group home back, people had limited abilities, and then he

moved to -- after 20 years, moved here to Manhattan from Brooklyn to be closer to me. But it turned out he was more challenged in this new setting. And now he's even closer to me, in more ways than one. It's a very advanced -- a lot of the people there are quite capable. He's been raising the bar and we've been raising the bar for him.

So the thing about the group home, it's community living. I know we'll talk about that in a little while. But the most defining characteristic of Fred is that he's a survivor -- or he lived from the age of 4 to the age of 20 in the Willowbrook state school.

>> MIZUTANI: Yeah, as you describe in your book. Willowbrook is a topic in its own right. And listeners who follow disability history know that it was the biggest state-run institution for people with disabilities, and was officially shuttered in 1987. It's impossible to even talk about Fred and his life without reflecting a little on societal beliefs then and now. Big difference over the years.

>> GOLDSTEIN: That's an interesting point. Society doesn't know that it's happening until it's exposed, and say, "Oh, that's so terrible. We had no idea." I don't buy that story at all. But Dr. Wilkins and Geraldo Rivera, they busted Willowbrook in 1972. It was on the news. And all of a sudden, the two different governors we had are putting money back into the system. That kind of money that's being threatened to be taken away now. So I always wonder how far we've really come.

It was a place built -- it was called a school, but a school is where people learn things. Here, there would be a piece of paper on the floor, and there would be 50 residents fighting to play with that piece of paper. We would visit every other Sunday, which was Visitor's Day, and

we would see sparkling walls, but always a smell of urine. We'd see a lot of kids sitting around -- children sitting around with football helmets, because they banged their heads.

Most of these children, and there were three staff members for every 50 children. So there weren't a lot of hugs going on. A lot of the kids there were abandoned by their families. And so, when my father and I would walk into this building to pick up my brother, there would be one, then three, then six children who were up to my waist, and I was 8 years old, and they'd start screaming, "Daddy, daddy, daddy, daddy, daddy."

>> MIZUTANI: Oh, wow.

>> GOLDSTEIN: They'd come running up to you and grabbing you and hugging you. They'd just -- big, big smiles. And I'd have to peel their little hands away, saying, "Oh, I'm not your daddy," and I'm looking over their heads for my brother. There was Nurse Hooks -- I'll never forget her name.

[LAUGHTER]

Yeah, it's an interesting name. Either she had a feeling for Freddy, or she knew or they knew that Fred had family and we were coming. But we'd always get updates about Fred. But she'd come out from the back with Fred, and then Fred would see us, and he'd come running towards us as fast as his little legs could take us. And then we'd get outside and slam that big, green door, and smell the fresh air. It was just so different from the inside.

And none of these kids got to go outdoors, because there wasn't enough staff to supervise. So they spent their entire lives indoors. And the only time Freddy got out was when we came by, or if we took him home for a visit. When I talk to Fred now, he tells me

Willowbrook is old. He told me just yesterday, he took his clothes out. We were talking about 1972.

But people learn by watching. And the institution is that they were away from society, and the doctors told parents what they thought the parents wanted to hear was tell the family that the baby died in childbirth, or just dump 'em. They had no idea this medical model. They couldn't fix it, so they had no idea what to do.

So with society, the social model now, we fix society. And we have early intervention now. And we accommodate people's needs. So the bar keeps getting -- you get to the point where -- I mean, my brother writes poetry. So go tell that to the doctor who didn't want to operate on his left eye, which was hooded. They said, "Oh, well, he sees well enough for a retarded person."

>> MIZUTANI: Oh, goodness.

>> GOLDSTEIN: This was the psychologist at that place. And he was essentially a criminal --

>> MIZUTANI: Terrible.

>> GOLDSTEIN: Because they were wondering why my brother was falling down so often. It was because he couldn't see out of one eye.

>> MIZUTANI: Well, there is just -- so much has passed. So much has happened, and you certainly had ample material to work with. I mean, this podcast is about processing complex feelings through art, and I can really see (chuckling) why it wound up the way it did. I mean, ancient humans recorded their lives through art, perhaps as much for themselves as for others.

So I'd like to hear more about how it started for you, Liz, and what were your motivations?

>> SARGENT: Well, I think Allan's story is one, that horrific idea that I think a lot of people have grown up believing that all assisted living is like that. And so thinking about this wide variety of people in my family, that I'm thinking about their care-taking as they grow older, is just frightening to me.

And what started me was I was in New York. My whole family is spread across the country. I'm in this point in my life where I'm feeling stability with the man I'm about to marry. Working in my career, trying to be creative, taking the risks to be an artist -- and feeling this pressure with that responsibility for these people in my life.

And at this time, my parents are aging. My sister is getting a little bit physical, a little bit violent toward them, and they're calling me to sort of calm her. So in the middle of my crazy New York day, I'm getting these phone calls to sort of ease her and convince her to take some space. And then at the same time, my sister who has borderline personality has stopped talking to the family, and nobody knows what's happened to her. So there's all these crazy ideas that maybe she's been trafficked. Like, we have no idea.

And just sort of being trapped in this emotional moment, losing my personal goals of being an artist, and wanting to care for these people, I sort of thought of this way of combining it all together. People are always looking for documentary ideas or dramatic narratives, and I'm sitting here living it. So it sort of gave me this moment to take over the narrative, to take control of it, and to also make action.

And part of the documentary was to ask my parents and confront these questions of what are we going to do? What is the plan? And through that, asking questions about -- in my situation, my parents chose openly to adopt people with special needs. And it's a very interesting situation to think about. If they knew what that takes, and what it would feel like in their old age, you know?

And if that is also -- there's a different -- even though we all grew up -- we're very close. We're definitely a family, but there is a huge age range in our family as well. And with a large family, there's sort of this thing of "not it." Everybody sort of takes their place as a certain type of person. So there wasn't anything like Allan, who was it's almost assumed, and there is a huge weight to that. But there's also a huge weight of nobody stepping up because of this -- and having all these options, and no options.

And so that's sort of what pushed me forward, is mainly the fear and trying to do everything, which I think is also a sibling thing of trying to take care of the world -- a learned thing as we grow up.

>> MIZUTANI: Yeah.

>> SARGENT: And I think also -- I was reading this book -- this book by Oprah about trauma and what happened to you, and thing there's like a beauty and a trauma to being a sibling and seeing the world like this. And I think they can both be -- we can hold those hand in hand. She says something about all of us want to know what we do, what we say, and who we are matters. I think something about these actions and standing up for your family and being there, and

making these decisions, these very huge ethical human decisions, felt important for a wider audience to see and feel that impact. I think universal questions that we have.

>> MIZUTANI: Allan, how did you get started?

>> GOLDSTEIN: Liz, it's been documented that -- I'm not ignoring you, Jean.

[LAUGHTER]

But it's been documented that the women siblings typically take over. And if my sister had been born, who knows if she would be doing what I've been doing instead?

I guess the question is, how did I begin writing? I was an actor for more than 20 years, which means that I became a really good bartender. It just seemed that just my father had been dead for 10 years, and I think my mother had just gotten ill with a cancer, and I needed to tell this story about my last moments with my father. So I enrolled in a personal experience writing course. And I'm still with that teacher -- of course, it was over 20 years ago. So that's how I began writing.

So the art began with a need. I needed to write; tell this story. And I had always written in the past, but never had the patience to be a writer. I think that's what the 20 years as an actor helped me do. It taught me how to be centered -- that, and yoga. But my motivation was my mom's death spiral. Visits to the hospital, the operations, the failed operations. The being hospitalized. The being in a hospice. I found that the writing was a way to shed sadness or confusion, and certainly anger.

And what I learned, which all writers and all artists know, that we write to get it out of our system. Essentially, to understand. I would tell all my students that once you write it down,

put it piece of paper, crumple it up or get it published, but it's out of your system. But I've been learning recently, no, it's not out of your system.

[LAUGHTER]

It's been understood a little bit better, but it still really makes you angry or upset.

>> MIZUTANI: Doesn't it provide a wee bit of distance, though?

>> GOLDSTEIN: Oh, well, living it -- I was speaking with Liz earlier, that the book was essentially a journal of my brother and I meeting weekly, and what happened. And so the writing was really to not lose those moments. Because I find if I don't write about something, it's gone. But here, it's always here.

>> MIZUTANI: Wow.

>> GOLDSTEIN: And I think it was a way for me to establish our new reality. So the distance is certainly with the past family members, and his and my interaction with past family members. We have a perspective now; like, I never knew a particular aunt was so lonely, but I discovered that together with Freddy. So I understand your question. You need distance.

But this was in the moment, and again, the need and the motivation was right there. I was never at a loss of what's next? Something happened that weekend, a highlight, and that was the basis; that was the theme of that chapter.

>> SARGENT: I love, Allan, in your work, I feel like you've got such also soft, sensitive moments, like the ice cream story. There are these very intimate, quiet moments that happen, where you're just sort of seeing eye to eye with your brother. I think those are really lovely as well.

>> GOLDSTEIN: Thank you.

>> SARGENT: Not just capturing and drama and the need and the conflict, but also these very, very special, intimate, human moments, that are hard to even have with typical people sometimes. But there's – yeah, they relationship is different.

>> GOLDSTEIN: Those are probably the important moments, because that's what connects. They're connected.

>> SARGENT: I was always thinking about what Jean was talking about. I was thinking about disassociation a lot, and these narratives about pulling myself out of the story completely, and being able to see it objectively. I think that's a lot of why I do this as well. I think for the documentary, it was questions that I didn't have the emotional vulnerability to sit down and ask my parents. And something about hiding behind the camera and asking them these questions gave me this armor -- even though they could turn around and ask me questions, but in a way, it was like it just forced them not to avoid it, and for me to be brave enough to ask it.

And I'm writing narrative scripts right now, and I think there's something about thinking about these difficult situations as a film, or as a story, and also finding a solution through them. And seeing how I can be different, or rethinking the characters in my life in the story, and maybe seeing them in a new light. So I found that really helpful, actually. It's a lot easier than feeling like I'm spinning out in the world; like controlled by other people's needs and emotions. Which I think growing up in a family like this can happen to you. So.

>> GOLDSTEIN: You're the boss. You're controlling the interview. You're controlling the line of thinking and sharing information. And it's to you, basically you're digesting it. You're cutting up the meat in little pieces so that you can digest it.

>> SARGENT: Yeah, and I am choosing how much I am willing to offer of myself, which I think that in my life, being a caretaker, and being in these situations, where there are people in need across the board, I've felt taken advantage of in times -- because other people's needs were greater than mine. So in this way, also, I can protect myself.

>> GOLDSTEIN: I could offer -- stick my nose in your business.

>> SARGENT: (Chuckling) Good.

>> GOLDSTEIN: It's that I know the memoir that came down -- I spoke to some famous memoir guys, and they always said, "What about you? What about you, what about you?" So be prepared (chuckling) that when people are taking looks at your footage, they're going to say, "We want to know about you."

You may come across just from your questions, I think the audience may catch on, "you." I never did focus on me, and yet it's all there. So you're going to get hit in the head, "What about you?" But stay strong with what you're doing, because "you" is there (chuckling). You've created this art.

>> SARGENT: But on that note, and I'd be curious your experience, looking at yourself within your memoir. I have done some test edits on my documentary, and I think that I get people who it resonates deeply with. Some people who also find some dissonance in it. I think it's interesting that the sibling or the disability community resonates deeply with it. And sort of outsider communities sometimes are critical about my strong feelings within it.

Which I think I've learned a lot about myself and my reactions within these situations. It has been very therapeutic to me, and given me a greater -- a better idea of what the situation

is, and being fair to the people involved. But yeah, putting myself in there and being a voice or a narrator or an active participant has been something I'm still figuring out in the process.

>> GOLDSTEIN: It depends on who's criticizing you. A lot of people, if they're outside the disability world, that don't have it in their family, they're intrinsically ableists; and therefore, they don't see you dealing with a person who's a person and has -- wants work and wants love. They don't get that. So they may even be uncomfortable with what you're showing them. Or they don't understand your passion. In the long run, they're going to really love what comes out.

>> SARGENT: Yeah, but I think there's also this carefulness about being -- especially if you're outside of having these very close relationships with people with disabilities, people are uncomfortable with the idea of anger or resentment or -- and I think that's a really important part of the entire story. And part of that anger and resentment often stems from deep love and protection.

So for me, I'm just figuring out how I need these stories to land, and what the lesson is at the end. Because I think that having all of those emotions and complicated situations, where you're not your best self, they're not their best self, but that is actually what humans are (chuckling), not always their best self.

>> GOLDSTEIN: Yeah, yeah.

>> MIZUTANI: It's true. Well, the arts create community by depicting shared events sometimes. And you've talked a lot about the responses of others to your work. How do you think others have benefited?

[PAUSE]

>> GOLDSTEIN: Liz?

[PAUSE]

>> SARGENT: (Chuckling) Um, I think just seeing that these stories exist. For me, just a part of the process of finding these communities has been really important to me. Not feeling alone, such as the Sibling Leadership Network, and INCLUDE. And so I think creating these stories for our community, that people who are experiencing this, is just consoling, in a way. But also, I think a lot about this -- about the wider audience, and how we don't really realize that everyone is closely related to somebody who has a close relationship with someone with a disability. And I think reconsidering or understanding -- I don't know if I'm saying this very well.

[PAUSE]

The people -- hmm. You can edit this out.

[LAUGHTER]

I just think we're all closer to disability than maybe we know. And I don't think it's really talked about in communities. So I think seeing these narratives and being able to talk about them is helpful.

>> MIZUTANI: No, I actually think it's extremely helpful. I mean, this is how we create norms. These stories are super important. I'm sure that many people who gravitate to your work gravitate because they also have disability in their families, and they'd like to see models and ideas on how other people cope, other perspectives. But it's way beyond that. Somebody who's never really thought about it can learn, too.

So I think it's pretty amazing. I mean, art does influence society by changing opinions in the end. Do you agree?

>> GOLDSTEIN: One person at a time, right? Jean, what was the question?

[LAUGHTER]

>> MIZUTANI: I let you guys run with it because we were talking -- well, what we were supposed to be talking about was the kind of responses that you've gotten to your work. And I heard a lot of answers already. Is there anything we've left out?

>> GOLDSTEIN: I find that -- yeah, I think this may just be repetitious. People do feel better prepared for dealing with similar situations that they anticipate will arise. On the other side, people have been saying it's more of a light on to the unknown world of disabilities. It's like an introduction to disability world.

But the bottom line is, we read to learn how others dealt with a situation that we're presently in. And what's happening is the response is that people are understanding that they have choices. And that the people with disabilities can and do have preferences, and do favor this food over that food, or surprised when they can choose where they may live. When my brother learned that he could move from one residence to another, that was like discovering that the sun comes up every day. And so it builds a great deal of self-esteem.

I think the responses are, to the book, anyway, is they enjoy seeing the development of a brother relationship. And they -- what did I have here? Oh, I have something that I wanted to share with you. And I only know this because these are quotes from reviews of the book. They

see that the book is a powerful reminder of the importance of providing a person-centered life. That's something Liz will be working on with Anna.

Or it's a look on the ways that we treat those whose brains work differently. How we make them second-class citizens. And then, that somebody who's labeled with intellectual developmental disabilities can also be creative and is a feeling human being. The world, the people outside this world just don't know this, as we found from what Liz was saying.

And that's -- the artist is there to reflect society to society; see what's going on, to understand themselves. Even in the time of Galileo, you had the ballad singer, and he was telling them, "Yeah, you know what? You don't have to turn the other cheek. Or you don't have to make the shoes for the rich guy. You can make them for your kids." So the artist is -- that's the job. And we're not thinking, "Oh, yeah, this is my job. I want to reflect." At least in my case, I'm being selfish and trying to understand what was really going on. But I guess it's being willing to share it and show it to others, so they can benefit from what I discovered.

Liz, you were going to say something?

>> SARGENT: I may have forgotten.

[LAUGHTER]

>> GOLDSTEIN: That's my disease. I always tell my students, "Look, I'm going to have to butt in here, because I'm going to forget. You're young, you're going to remember. I'm going to forget."

>> SARGENT: I guess I was thinking about how, for me, it's very personal. I feel like I just want to capture this moment that I can feel is very important with their interesting lives. And I think that if people can relate to another human, if you can offer that snippet into a life, and someone can

-- they resonate with them, then you will fight for them and be active. I don't make political work. I try to make very human, personal work. And I think that if you care for another human and know them, then I think you'll protect them and think differently in your --

>> GOLDSTEIN: I think that's what's gone on with the film and with the book, is that the audience gets to know the individual.

>> MIZUTANI: Right, right.

>> GOLDSTEIN: And then you're dealing with a person.

>> SARGENT: Yeah, and if an artist's work is reflecting the world, it's just about acting to that narrative. We have a very specific access into a world of people. And I was thinking about privilege and how it's a privilege and it's difficult for people who have family with disability to share their story, because the weight of their daily life is so much. And so for us to just be documenting this in any way is very important, because that's the work that disappears in the world. Because those people don't get to have that voice, because they don't have the time or the energy or the clarity or the selfishness to take that space for themselves.

>> MIZUTANI: Well, there it is, because the final question is: What do you think is the legacy of your work? It's funny, you two are ahead of me on the questions all through the conversation. I think the legacy question is an important one, though, because art is lasting.

>> GOLDSTEIN: Art is -- yeah. Liz, did you want to go? It reminds of the story. There are two actors on stage, and the sound guy rings a phone by accident. So one actor says to the other guy, "Pick it up." So the other guy goes to it, he says, "It's for you."

[LAUGHTER]

Liz, I can take it first, if you want.

>> SARGENT: Yeah, go for it.

[LAUGHTER]

Actually, let me go first, because you'll summarize well. For me -- in some ways, to me, the documentary is the legacy of my parents who have given their life to their children and supported many children with disabilities their entire life. I think they are unsung heroes. It's also giving my sister a life and a voice to a greater space or audience. And I'm obviously within that. But I think I make the work a lot to process these ideas. And if I can just get through this life emotionally stable, (chuckling) understanding these situations in a deeper way, then that's enough for me.

>> MIZUTANI: I do think others will benefit as well, though. There's no question in my mind that they will.

>> GOLDSTEIN: So there.

>> MIZUTANI: So there.

[LAUGHTER]

>> GOLDSTEIN: When I think about legacy, which after completing "Fred and Me," I told my wife, "This is really essentially our legacy. When we're dead, this is going to live on." That's why I'm trying to get it into all the libraries. But I think what I hope comes out of the work that I've been doing is that people, all people will understand that being different is not being less-than. And that difference is natural.

I told Fred that we'd be talking today. And so I understood that we might be discussing this question. So I asked him, what is the legacy? Well, I said, what do you want people to remember about you? And we went through a list.

He said he washes the table. He likes mobile phones. He has cars that he runs by batteries through the house, so watch out. The big secret, but he wants me to share, is that he had a girlfriend. That he goes to camp. That he likes riding the bus, but not the subway. Even Access-a-Ride is okay. He likes arts and crafts, soap-making. They did a lot of that. I ended up with a lot of soap for a lot of years.

He played keyboard in Daniel's music, and now he does the drums -- pre-pandemic and hopefully with post. And he likes to visit my house overnight, and that he is strong. He is resilient having to deal with this COVID, and he likes to go places. He and I presented his story to the Best Buddies International conference for a couple years.

And I guess the big one for him that he wanted to leave us with is that he loves new baseball hats. So maybe that's what he needs on his tombstone, a baseball hat.

>> MIZUTANI: That's beautiful.

>> SARGENT: You know what I love about that? That's everyone's legacy. Those little things are actually what life is made up of, right?

>> MIZUTANI: Fred is famous now. He's quite well-known.

I want to thank you both so much for sharing this conversation with us. I've enjoyed every minute of it. Thank you very much for participating with us. And I want to say thanks and bye to all of our listeners. Catch you next time on "Disability, Inc."