

Raquel Rosa (00:00):

Hi, everyone. This is Raquel Rosa. I am the community engagement and advocacy coordinator at NDRN. This means that I support all of the P&As with intake, information referrals, outreach, and I support the PAMI Advisory Councils. So speaking of outreach, we're going to talk about self-advocacy and storytelling, because as advocates, it's really important that we are standing beside people with disabilities and encouraging people to share their lived experience authentically and safely and [00:00:30] in a place that it is valued.

(00:33):

There is nothing better than getting to know people's stories right from the source. So I am joined today by one of my dearest friends. We have been together since, oh my gosh, 1995. And Nanette is very close, very special to me. And she's an author, she is a person with lived experience, she is an advocate, and I'm really excited to be working on this with her today. She's going to talk [00:01:00] to us about her story and how she came into this space. So Nanette, would you introduce yourself to the people and we'll get started?

Nanette Opperman (01:08):

Sure. My name's Nanette Opperman, and I am a C2 spinal cord injury and brain injury survivor. I was injured in 1982 when I was 3 years old and was in a car accident. [00:01:30] And I have three brothers and two sisters. And so we come from a large family or I come from a large family. And then I am married and no children. I work full-time at multiple jobs. Well, I work full-time at one job and I have multiple side hustles as most people have these days. And [00:02:00] I am also a writer. I write children's books and I tell my story through them.

Raquel Rosa (02:09):

So we're going to get into some dialogue. I have some questions for Nanette to unpack for us. I will share some outreach and engagement ideas. We will finish out with some recommendations, and then we're going to have a great evening or day depending on when you're watching this. So Nanette, if [00:02:30] you will start us off with telling us about your aha moment, because not everybody is an advocate from the beginning. So tell us how you got there.

Nanette Opperman (02:38):

Well, there's several ways I've gotten here, but the main thing was when I was in college, I got my degree in English and then that qualifies you for everything and nothing. So I thought, "Well, I'm not getting a job just based off of this." I didn't know how to hone the job search and stuff. I asked my mother one day, "If I wanted [00:03:00] to do writing as therapy, what would that be?"

(03:04):

And she said, "Therapeutic writing."

(03:06):

And so I Googled, I don't know if it was Google then, but anyway, I looked up what that would fall under and therapeutic recreation was the topic. So I went back and got my therapeutic recreation degree on top of the English. So I have two bachelors, a bachelor of arts and a bachelor of science. And while I was doing that, I did bibliotherapy with [00:03:30] Eastern State here in Virginia, and I created a program that was a bibliotherapy program. And we read books, and I came up with questions to go along with it. And then we discussed different aspects of the book, how it related to them, et cetera.

(03:46):

And when I finished that, I got my CTRS, which is the certification, but I kept interviewing and interviewing and interviewing and I couldn't find anything. So I eventually got a job, but not in that field. [00:04:00] While I was at that job, I got bored. It's a normal job. I'm an admin, but it wasn't very stimulating. So I thought, "Well, what can I do that would stimulate my mind, but also serve what I wanted to do, which is the people and to encourage people to keep on going and whatnot?"

(04:20):

And so the idea that came to mind was writing. And so then I thought to myself, "Well, what do I want to write?" And the idea that came to mind was, "Write your story."

(04:29):

And then [00:04:30] I was like, "But I don't want to write a long story and I don't want to write a biography, because I don't know my whole story." I was 3. There was a lot that went on that I just was not privy to because I just was living it.

(04:43):

And so, I decided I'd write children's stories because my experience came from when I was a child. And I thought that was important to tell because as parents, I've seen the other side. I've seen the parents all [00:05:00] worried about their children, how they're going to grow up, what they've lost, what they haven't, all the what, what, and what's going to happen. So I was like, but no, you rarely see it from the child's perspective.

Raquel Rosa (05:16):

Right.

Nanette Opperman (05:16):

And so, I felt that was important to tell and to illustrate not only to children, but to the parents and be like, "Look, we are not worried about what you're worried about yet when we're that young. We're just living in the moment."

(05:30):

[00:05:30] So that was my aha moment. And then because I was doing that and I was trying to sell the book, it became quite apparent that I had to also start publicly advocating instead of just privately for the disabled, because the books are all about me and being disabled. So I thought, "Well, I better get into this [00:06:00] and be comfortable with it." Because I'm comfortable living as an example to my day-to-day people and peers, but it's a whole different world doing it in the public.

Raquel Rosa (06:11):

Yeah. Yeah, it is.

Nanette Opperman (06:12):

What was my other aha moment? Oh, I recently was in the hospital a couple of years ago, 2023, and I think I got COVID, but I didn't go to the doctor to get tested. And then by the time [00:06:30] I did go to the doctor, COVID was gone, but I was reaping the ramifications, because my oxygen levels were low, but they're always low. What happened was my CO2 levels rose too high. They didn't figure that out till weeks later. And so, I consequently suffered a lot of different things that I didn't realize how much one

has to advocate for oneself in the hospital. And I haven't been in the hospital [00:07:00] since I was in middle school. So I was in bed for three weeks. That was a death sentence. I should have never let that occur. I should have been out of that bed the day of. I shouldn't have been in bed at all.

(07:17):

So through that experience, I had a lot of aha moments about self-advocacy and demanding, and demanding whether people agree with me or not. I found that when [00:07:30] I was demanding, my sisters were like, "Well, why are you being so mean?"

(07:34):

And I'm like, "Because if I don't, they don't listen. They literally do not listen."

(07:41):

Even in the intake when I finally went to rehab because I couldn't walk still, which is insane because when I went into the hospital, I was walking, so there should have been no reason that I couldn't walk. Anyway, and when I say walk, just so everybody knows, not very [00:08:00] well, just minimally, but still very important. Because if I can't transfer, then I can't go to the bathroom. I can't do all the things, because I can only use my right hand.

(08:12):

So anyway, backtracking. When I went into the nursing home and they were doing the intake form, the lady asked me three times what insurance I had, and each time I said, "Anthem."

(08:27):

And she's like, "Medicaid?"

(08:29):

I said, "Anthem."

(08:29):

"You [00:08:30] mean Medicaid?"

(08:32):

I said, "Anthem." I'm sorry if I'm yelling.

Raquel Rosa (08:37):

You're not yelling.

Nanette Opperman (08:38):

She just could not get past the idea that somebody in a wheelchair would have normal insurance through my job. And it's like, "I don't know how to be any clearer. I said Anthem, I'm not on Medicare. You are not [00:09:00] listening. You are assuming." And I found that a lot through... So anyway, those are my two aha moments. You have to be an advocate. And then, anyway.

Raquel Rosa (09:12):

But I think what you're saying makes sense that sometimes you're thrown into the deep end of advocacy.

Nanette Opperman (09:18):

Yes.

Raquel Rosa ([09:19](#)):

So on one hand, you're talking about your lived experience from youth to adulthood and telling your story on this side, but [00:09:30] through the eyes of a child.

Nanette Opperman ([09:31](#)):

Yes.

Raquel Rosa ([09:32](#)):

But then the other part is in a really critical situation, having to sound the alarm to caregivers and other professionals in this space to listen and pay attention to the details. And those are things that unfortunately are not automatically part of the-

Nanette Opperman ([09:52](#)):

No.

Raquel Rosa ([09:53](#)):

Yeah. So your aha moment has a lot of-

Nanette Opperman ([09:58](#)):

A lot of stuff.

Raquel Rosa ([10:00](#)):

[00:10:00] A lot of stuff. And I mean, I guess to that end, advocacy is a journey. We're all going to unfold at different moments, and you've got some pretty pronounced experiences that really helped shape-

Nanette Opperman ([10:14](#)):

I mean, I've been thinking this a lot, how different life is as an adult versus a child with a disability, but that really brought it home. This is a different ballgame. You've got to learn how to be your own advocate, because nobody [00:10:30] else is going to stand up for you. Your mother's in her 80s and falling apart, and your siblings are all over the world, and so it's you or nobody.

Raquel Rosa ([10:44](#)):

Right. Well, I mean, we're in our own skin all the time, right?

Nanette Opperman ([10:47](#)):

Yes.

Raquel Rosa ([10:48](#)):

And to that point, it's not that your family doesn't love you, but they're not-

Nanette Opperman ([10:52](#)):

Oh no, they do.

Raquel Rosa (10:54):

... there. And you're like, "It's just me, myself, and I, and I've got to say the things."

(10:59):

And [00:11:00] I would also say, and I think this goes back to my opening statement where people who are advocates, not necessarily self-advocates, it is up to us to develop the expectations that people with disabilities have of us, that it is listening, it is asking questions, it is being present, it is being safe, it is honoring your [00:11:30] decisions. And if you asked me... Well, I mean, obviously we have a friendship, but let's say that we didn't know each other like that, and if you asked me something to do something to whatever, as an advocate, I'm going to do that because that's my job.

(11:49):

That being said, I'm not going to make decisions for you. I'm not going to jump in front of you unless there was a real reason to get in front of you, and that is your safety is at risk, there is something really bad going [00:12:00] down. But if you're just saying whatever the thing is... Let's say that we were going to a restaurant, we just happened to be entering a restaurant at the same time, and there were some issues with access. I would not jump in front of you and say, "Oh, well, you've got to do this." But, "May I help you? Is there something I can do? Can I talk to somebody? Can I get somebody for you?" That's a different thing, that's being present with and not making assumptions for. And [00:12:30] so, I think that that's really important in that choreography of advocacy and self-advocacy.

(12:37):

Yesterday, I was at a poetry reading in Washington DC, and there was a woman in attendance who uses a walker, and she got into the second row, and she seemed to be totally cool, but I happened to wave her down and I said, "There's an empty seat here if you would like."

(12:52):

She says, "I'm good."

(12:53):

I was like, "All right." I was like, "Have a good time."

(12:55):

And that's it. I wasn't trying to tell her [00:13:00] where to be or what to do, but there's a free seat here. I was in the front row, by the way, so there's a free seat here if you'd like, and she was cool, and that's what it is. You just hold space and you respect whatever it is. So, yes. Well, we've got a lot more to get into here.

(13:21):

So as this conversation unfolds, Nanette's going to share her story, her perspective, her wisdom, [00:13:30] and I will share with all of you ideas for outreach and engagement, because as folks within the P&A network, we're really tasked with meaningful outreach and engagement, and we've got a number of audiences. We've got people with disabilities, we have family members, service providers, people who are elected officials, people who work at state agencies, people who work at federal agencies. We've got folks all over, and so it's [00:14:00] really important for us to craft messaging that really hits the heart of what we're doing. And it's really important for us to make sure that we are meaningfully and authentically including people with disabilities in those messages and campaigns.

(14:19):

So some of the ways that we can do that is we can interview people with lived experience. We want to be led by our P&A values. That means that people are entitled [00:14:30] to self-advocacy and self-determination, that we are honoring people's existence and experience, that we are believing and giving fidelity to their first person perspectives. You can do this through blogs, vlogs. You can do a social media campaign. You can have them help write an op-ed. So there are lots of ways that you can have interviews. You can do something like this where if we're very lucky, we're going to have this on [00:15:00] YouTube and on our social media. I really hope I'm not jumping ahead of things, but that's what I'm hoping for. These are just ways of helping get stories out because it legitimizes this experience.

(15:11):

Part of advocacy is telling the story, and we just want to make sure that we are putting real life in front of that, that it's not just the professional advocacy space. So moving forward, Nanette, you have three books, [00:15:30] and I think there's a fourth on the way?

Nanette Opperman (15:33):

There is a fourth on the way, Nanette's Thanksgiving Adventure.

Raquel Rosa (15:37):

So if you could walk us through the books you already have.

Nanette Opperman (15:42):

Okay. So the books I have, I have, Nanette's Grandest Adventure, which is about my origin story. I decided that I actually had the idea for the second one first, but the first one had to come first so that you knew why she was in the wheelchair. I thought that was kind of important. Plus, I was writing these also [00:16:00] for my family and my siblings and their kids and hopefully their kids. There's certain stories I want them to know from my point of view. No matter where I live, they'll have the story, because we're all over the place. So that's Nanette's Grandest Adventure.

(16:21):

And then I wrote, Nanette's Library Adventure, which is just about going to the library, which was a big deal when we were kids because it was free, [00:16:30] it was close by, and I loved reading. Because in books you can do whatever you want to do. You can be on the moon, you can be in the forest, you can be tall, thin, fat, skinny, walking, not walking. And so, that really appealed to me. It shows family dynamics, it shows problem solving skills, it shows problems that the world creates, like potholes and stuff.

(16:58):

And then, Nanette's [00:17:00] Halloween Adventure is my latest one that's out. And that one is different, because it shows that inclusion is not just for the disabled, it's for everybody. And so, in the book, Nanette gets to include her friend in the experience that she has daily by letting her use her old wheelchair. She was lucky enough to have two at the time, because she had the old one still and the new one. So she got to share in the experience, [00:17:30] which is including her in my experience, in Nanette's experience. And that's important because people don't know until they know, and you can't expect everybody to know how your life is because they're too busy living their lives and we just can't live every life. We just can't.

(17:49):

So this is a way to be inclusive, and it's a memory that she had actually that I was not going to write about. But she visited [00:18:00] me while I was in the hospital at that hospital experience that I told you about and said, "Oh, that was my favorite adventure when we were little."

(18:10):

And I thought, "Oh, now I have to write it."

(18:12):

Anyway, that's how that came to be. And then the fourth one is going to be, Nanette's Thanksgiving Adventure. And that's more about how you can use a wheelchair, but also not use a wheelchair, which apparently is a huge thing that people are having an issue with these days is, "How [00:18:30] dare you use a wheelchair when you can walk?" Anyway, does that [inaudible 00:18:37].

Raquel Rosa (18:36):

Yes. Well, I wanted to get into some of these subtopics, but I did want to say that I thought it was interesting how you were talking about just what literature does for us, that we're able to live different lives. And so, to the point of inclusion, this really does give us the opportunity to expand what [00:19:00] that experience is. I think that as people, we are very interested and attracted to characters and stories, whether it's on movie, television, books, what have you. And storytelling has been part of the human experience since the beginning of time, and here are ways where we can expand what those experiences include. Because there aren't many, [00:19:30] and there aren't many first person books, and I don't know that there are a lot of first person children's books. So you're also in the shoes of a pioneer.

Nanette Opperman (19:44):

Well, and not only that, mine are very normal. They're not, Nanette went to the moon. They're realistic, and in some ways that's not as exciting for a child, but in [00:20:00] a lot of ways, I find that much more accessible.

Raquel Rosa (20:02):

I think you're right, because to the point of representation and intent and influence, what are you telling other children with disabilities. I mean, these are everyday experiences.

Nanette Opperman (20:14):

Every day.

Raquel Rosa (20:15):

People have friends, people go trick-or-treating, people have Halloween, or people have Thanksgiving, sorry. These are everyday experiences regardless of where you live, what you do, wheelchair, no wheelchair, this is every day. And sure, [00:20:30] it may not be the adventure of going to the moon or traveling time or whatever. Maybe if Nanette decides to go into a sci-fi route, she can do those things if she chooses, but to the point of just real life, this is showing possibility. So I think you're showing children, "This could be your life." You're showing their... And I don't want to put words in your mouth, but this is the way I receive it, is that you're telling children with disabilities, "This could be your life." [00:21:00] You're telling their friends and their schoolmates, their neighbors, "This is normal life."

Nanette Opperman ([21:06](#)):

We're not scary.

Raquel Rosa ([21:08](#)):

No. So if you could unpack a little bit more about what the representation is for you, what does that representation mean as an adult telling children and telling these other folks, "This is a normal experience," and just hopefully that they would abandon any fear?

Nanette Opperman ([21:30](#)):

[00:21:30] That is my hope that it helps them approach children. I want to say before third grade, kids are very approachable. They'll come up to you, they'll say, "Well, how do you go to bed?" Or, "How do you do this?" They're much more approachable.

([21:45](#)):

But after third grade, they don't want to come anywhere near you or they just stare at you. And so hopefully this will make it so that they can catch other children at that age and become friends so that [00:22:00] it's from a young age that they're friends. So that it's just like anybody else. And there's going to be people that are not going to like you, and that's fine. That's normal. There's always the outsiders. I mean, there's a reason there's books about that. But hopefully, this will get the people that are on the verge.

([22:25](#)):

When I met Nolan, he was like, "Well, I don't understand what's so different about me."

([22:29](#)):

I'm like, "There's [00:22:30] everything different about you."

([22:35](#)):

When he was young, he told me a story about how he went up to this kid's house, knocked on the door and said, "Hey, can he come walk to school with me?"

([22:43](#)):

And the mother was just floored. She was so excited because the kid had Down syndrome and he was like, "I don't get it. What am I doing-"

Raquel Rosa ([22:55](#)):

Wow.

Nanette Opperman ([22:55](#)):

... "that's so amazing." And he's like, "I just want to play with him."

([23:00](#)):

[00:23:00] There's a lot of people like that. They're few and far in between. So I'm not trying to reach them because they've already got it. I'm trying to reach the ones that are almost there. And hopefully influence the ones that are terrified.

Raquel Rosa ([23:20](#)):

Yeah. It sounds like, I mean, what you just said really does braid together representation, intent, and influence. When you're speaking about your husband and that just [00:23:30] the open heart that he had as a young person, I think that speaks a lot to his upbringing and the values that he was given as a young person, and that he just saw people as other people.

Nanette Opperman (23:43):

He just saw them as they were.

Raquel Rosa (23:45):

Right. And to your point, unfortunately, that's not everybody's initial approach to this. I think what you said earlier about kids, there's a lot of curiosity, and then there's a lot of, I don't know if it's self-consciousness.

Nanette Opperman (24:00):

[00:24:00] It is.

Raquel Rosa (24:02):

I think to a degree there is that that's just kind of like, "Well, this is different and I don't know if I want to be associated with different."

Nanette Opperman (24:06):

Yes.

Raquel Rosa (24:08):

So I think there's part of that. I think there's also fear because... And it's not even fear of the person or even of their disability, but, "What if something goes sideways? I don't want to be in the mix."

(24:26):

And when you're a kid, especially when you're a kid, I think [00:24:30] the kids have fears, and I think parents have fears. The thing of it is, I mean, for anybody who... We've all grown up, we've all been kids at one point. We've all had scuffles on the playground. We've all taken our tumbles. We've all had things go sideways. And so to just normalize youth, I think that's a lot because yes, of course, we don't want to [00:25:00] put you in harm's way, but something happening, yes, something can happen and you could get a skinned elbow. Those things happen, and that's just part of growing up.

Nanette Opperman (25:13):

You said that it's the parents have fears, too, and the kids pick up on the parents' fears.

Raquel Rosa (25:18):

Right.

Nanette Opperman (25:20):

I cannot tell you how many times I was put to the side or kept to the side because the adults were worried. And what does that show the kids? It just makes [00:25:30] it that much harder.

Raquel Rosa (25:32):

Yeah. And by the way, like I said, if everything goes the way, I hope it will that this is going to go public, we are not at all against parents or-

Nanette Opperman (25:44):

No, we love parents.

Raquel Rosa (25:46):

We do. We love parents, we love our parents, all of that. We just want to be clear that there is a lot of unknowns, and that fear of the unknown, I think, is what gives people pause.

Nanette Opperman (26:00):

[00:26:00] Yes.

Raquel Rosa (26:01):

And that unfortunately, I think, has deeper ties than people are really expecting or that they really want to talk about. I mean, I think it's family members. I also think, going down the list, it's educators, it's other providers, it's neighbors and other community members. I think there are a lot of people who think treating people with kid gloves, I mean, literally and figuratively, that the kid glove approach [00:26:30] keeps people safe, and to a degree it does, but also it doesn't because the less visible people are, the more isolated people are, and the more chance that other things can happen. We just really want to make sure that we're approaching this as just human to human and that there is validity and vivacity that comes with just having a regular life.

Nanette Opperman (26:58):

Yes. To your point about [00:27:00] educators, when I was in kindergarten, my parents had to fight to get me into regular school, because they didn't want me at the regular school. And so, I went to a special school for half of kindergarten until I started to develop a stutter that I did not have prior to going to school. Because one of the other kids had a stutter and my mom decided, "No, that's it. I have to fight to get her into a regular school."

(27:28):

So she fought to get [00:27:30] me into the school that I went to that I won't name. Anyway, fought to get into the school. And then at the end of the kindergarten, they wanted to keep me back because I couldn't use scissors. My dad laughed in the teacher's face. Of course, I couldn't use scissors or had trouble using scissors. I could only use one hand. If you've ever tried to cut anything with one hand, you will notice that it's not easy.

(28:00):

[00:28:00] So they decided to push me forward to first grade. Then after first grade, they wanted to kick me out for no reason, other than they didn't want me there. And my mother went into the IEP meeting not knowing whether or not I was going to get to second grade or they were going to kick me out. The only reason I kept going was because the principal was absent that day, who was the main person that wanted me to hit the brakes. Then my first grade [00:28:30] teacher said, "Look, I'm going to solve this right now. You need a second grade teacher. I will teach second grade if you give me the same exact

class that I had before." And that was the end of it. After that, that principal wasn't there anymore, and everything else went, not smoothly, but there was no threat of me leaving. And this is after 504.

Raquel Rosa ([28:55](#)):

Yeah.

Nanette Opperman ([28:55](#)):

Is after the IDEA, and I was still fighting this, and it would've been [00:29:00] what, '84, '85? All of that to say it's fear and worry and concern and time. They feel like they're stretched thin with all the other students and they don't have the energy or time or the manpower, which I agree they probably didn't because they didn't hire anybody to help. So anyway, that was just something I wanted to interject real quick.

Raquel Rosa ([29:29](#)):

But you're right though, [00:29:30] that it takes a village, right? It takes a village to really support anyone and certainly people with disabilities. I think the fear really holds people back. I think you're right that people are stretched thin for any number of reasons, for all the reasons, but there's also, in my opinion, just not everybody is willing to put in the time and the imagination to make up whatever the solution is.

Nanette Opperman ([29:59](#)):

That's true.

Raquel Rosa ([30:00](#)):

[00:30:00] So we can and should be doing better. And hopefully these books will help unlock some of those sticking things.

Nanette Opperman ([30:08](#)):

And just a plug, I had many great teachers. They were not all-

Raquel Rosa ([30:14](#)):

Yes. So I'm just going to share a quick checklist for all of you in P&A land. Before you post your materials, make sure that you review all of your content. Make sure [00:30:30] that you are consistent. Whatever your organization uses, if it's person first language or identity first language, make sure that it's consistent. Make sure that you also check with the person or people you're interviewing. So Nanette might choose, "I'm a disabled person," but other folks might say, "I'm a person with a disability." So make sure that you are making clear of that in advance and that you're consistent in your materials related to [00:31:00] that person because it can vary from person to person.

([31:03](#)):

Make sure that whatever your packaging is, that your content that's going out on your website, on your social media, in other media, traditional media outlets, that your content and messaging is consistent, that you're promoting the same values, the same story, the same ideals. And also make sure that the content that you're creating meets a [00:31:30] number of target audiences, that it's not just the general public. I mean, that's of course very good, but that you're also connecting with other people with disabilities, that you're connecting with family members, you're connecting with educators and

providers, and you're also connecting with the general public. Because we are one, we coexist and it's really important that everybody is clued in to what this is, but that the messaging that you're putting out there really does meet the needs of those particular groups.

[\(32:00\):](#)

[00:32:00] So okay, Nanette and I are from a particular generation where rotary phones were still a thing, so that's our time machine. So I was hoping that you could share with us some of your reflections, any lessons learned, and any surprises along the way.

Nanette Opperman [\(32:17\):](#)

All right. So lessons learned. I think the biggest lessons I've learned in the last 10 years is that I'm enough. I'm a great person. I don't hurt people. I'm kind [00:32:30] most of the time. Don't tell my siblings. So there's no reason that I should think anything less of myself. I work hard, I play hard. So if people don't like me, that's not on me, that's on them. And that is like your whole childhood. You're just constantly thinking, I'm not enough or I need to do this or I need to change that." [00:33:00] And that's all fine and good to improve yourself, but don't be doing it so that people will like you. Do it because you need to. Exercise so that you have strong muscles for yourself, not for them, not for anybody else, but for you. So that's one thing I would tell myself if I were looking back.

[\(33:21\):](#)

Second, you don't know where you're going to go. Try everything. I would also say you need to be okay with yourself because [00:33:30] people will abandon you. You will have great friends, you will have true friends, but you will be alone in the end. In the end, you are the one that has to fight for you, you and God. That's it. So make friends with Him any way you see Him or worship or whatever, but that's the only one that you're going to have left in the end. And it's not because they don't care and it's not because they don't [00:34:00] love you. It's because their bandwidth only goes so far. And like you said earlier, you got to be comfortable with your skin because you're always there. You can't get away from yourself. You are there.

[\(34:15\):](#)

Trust yourself. When I was in the hospital this last time, one of the CNAs told me, "Why aren't they getting you up in the stander?"

[\(34:28\):](#)

I said, "Did they have one?"

[\(34:29\):](#)

And [00:34:30] she goes, "I think so."

[\(34:32\):](#)

And I thought to myself, "Well, there's therapists here. They know what they're doing. I'll just follow their lead."

[\(34:39\):](#)

Well, four months later they're like, "There's nothing else that we can do. We don't know why you can't walk because you can stand."

[\(34:46\):](#)

And I finally had the guts to say, "Well, do you have a stander?"

[\(34:50\):](#)

And they said, "Yeah."

(34:50):

I said, "Well, why don't we try that?"

(34:53):

And they're like, "Well, I guess we could." And then as soon as I stood in that, I could take a step.

Raquel Rosa (34:59):

Wow.

Nanette Opperman (35:00):

[00:35:00] And I could have done that four months earlier if I'd have trusted myself instead of saying, "Oh, well, the therapist knows better."

(35:09):

So I'm not saying that we're always right, but I would trust myself first. If the idea sounds plausible and it's not saying like, "Oh, you should step off that cliff," then go for it. Give it a try, and believe in yourself because you usually [00:35:30] are being inspired to do what you need to do. I think that's it.

(35:35):

A lot of self-love, a lot of knowing yourself and oh, there's always a way to do something. My sister in particular is always like, "Well, how are we going to do that?"

(35:48):

And I'm like, "There's got to be a way."

(35:52):

Whatever it is, whether it's driving, whether it's... If you want to ski, there's a way to do adaptive skiing. If you want to do gymnastics, [00:36:00] there's a way to do that. There's a way to become a doctor. There's a way to become whatever you want to do. I keep beating myself up because I'm not higher up in the world. And then I think, "But I don't like anything enough to put forth the effort to do that." It's really about what effort you want to put into it. So if you want to ski, by golly, there's a way that you can figure out how to ski, but you're going to have to put a lot of time into it. And [00:36:30] I pick what I want.

(36:32):

Oh, realizing... This was another thing, and this goes back to self-love. Nobody's going to understand you anymore. That was something I had to come to terms with. It was like, "Oh, I'm aging out, which means nobody's going to know where I was and how far I've come." Because they're all old and some of them dead and I've moved [00:37:00] on. You know what I mean? So that was kind of a scary thing for me. Especially with my mother aging. She really knows what it was like and how far I've come. So it's like nobody understands. I mean, I walk into a doctor's office now and they look at me like I'm crazy.

Raquel Rosa (37:18):

Wow.

Nanette Opperman (37:20):

"What do you mean you're not on blood thinners?"

(37:22):

And I'm like, "Well, why would I be on blood thinners?"

(37:25):

And he's like, "Well, look at you."

(37:27):

And I'm thinking, "I'm sorry, [00:37:30] what does that mean?" Consequently, I'm now on blood thinners.

(37:35):

But his fear was like, "By golly, you're going to have a stroke because you're sitting all the time and you're disabled and blah, blah, blah."

(37:45):

And I'm thinking, "I've been disabled for 30 some years." Well, actually 40 some now.

(37:52):

But anyway, so no, that didn't occur to me. And it wouldn't have occurred to any of the other doctors. [00:38:00] I can guarantee you they didn't bring up my blood pressure. Or if I walked into a clinic for spinal cord injuries, the first thing, they don't look at me and say, "Are you on blood thinners?" The point is they don't know you, and so they're judging you completely on what a normal person would be. And I'm not. My body is quite used to being the way it is. And so I'm not opposed to taking blood thinners [00:38:30] or any other supplement you want to throw at me. Not that blood thinners are a supplement. But anyway, the point is, I'm not opposed to doing those things to make you feel better and to make sure that... Because I don't know what's going to happen, but at the same time, do your homework before you throw things at me.

Raquel Rosa (38:53):

Yeah. Yeah. So I mean, what I'm hearing is that in that time machine conversation, it's know thyself.

Nanette Opperman (39:00):

[00:39:00] Exactly.

Raquel Rosa (39:01):

It's trust thyself.

Nanette Opperman (39:04):

Yep.

Raquel Rosa (39:05):

And I think it's also be willing to just be open, keep thyself open. I don't know that that's a quote either, but you know what I mean?

Nanette Opperman (39:13):

No, but we're going to make it one.

Raquel Rosa ([39:15](#)):

But I think that's true. And I think when we're young people, we just don't know what adulthood looks like or what the future is like. And both of us were in our 40s. We don't know what the next phase looks like. So all of this is just unfolding as life does.

([39:30](#)):

[00:39:30] So I do have a bonus time machine question. So we're going to go back to high school when you and I were first together. Would you imagine this opportunity and this conversation right now, 30 years ago?

Nanette Opperman ([39:45](#)):

Oh, no. I had no concept of the future, none whatsoever. One, I didn't think... Even if I did think about living on my own and stuff like that, I didn't think my mother would let me. She was so protective [00:40:00] and she had a plan, and I didn't know this, that I was going to live with my siblings. And I thought to myself, "Excuse me, you didn't ask me."

([40:10](#)):

Because I love my siblings, but I certainly didn't want to live with them. The funny thing about that is, is my life did not go that way. I never lived with my siblings. I either lived in college or with Nolan and my family or on my own. Anyway, so no, I did not see the future. I did not see anything. I [00:40:30] didn't see Nolan. I didn't see going to... I guess college was just kind of like a checkbox. Well, this is where you go next. I did not have any idea where I'd be working.

Raquel Rosa ([40:43](#)):

Or that you would be writing children's books?

Nanette Opperman ([40:45](#)):

Or that I'd be writing children's stories.

Raquel Rosa ([40:48](#)):

[inaudible 00:40:47] Because I mean, we've been writers for a long time, but I don't know that you thought of yourself as writing children's books.

Nanette Opperman ([40:55](#)):

No, and I didn't think I'd write actually after college, because [00:41:00] I never would've thought that I'd try and do it professionally, I guess you would call it.

Raquel Rosa ([41:07](#)):

Yeah. So that's what I mean, that's the, "Hello, 1995 or 1986 or 1997. We're on the phone from the future and Nanette and I are having a conversation right now on video," when this didn't exist back then.

Nanette Opperman ([41:23](#)):

No. Oh, my gosh.

Raquel Rosa ([41:26](#)):

Talking about-

Nanette Opperman ([41:27](#)):

We barely had the internet.

Raquel Rosa ([41:28](#)):

... [inaudible 00:41:29] on [00:41:30] self-advocacy and writing and publishing. I don't think our younger selves would see ourselves in this moment right now.

Nanette Opperman ([41:37](#)):

No, because I would've paid more attention to the publishing aspect.

Raquel Rosa ([41:43](#)):

Well, that's, I guess lessons learned is pay attention, but then also there's the surprises. And I think that surprises can often be really positive and exciting. I'm not surprised that we're still connected. I'm not surprised that we're still friends. I'm not surprised that we're still writing. But [00:42:00] the other elements, I wouldn't have predicted any of those things. And so, I just think it's a fun experience that we get to share.

Nanette Opperman ([42:10](#)):

I never would've thought that I would've worked at a psych facility. It didn't occur to me then. I had no... Yeah.

Raquel Rosa ([42:18](#)):

That experience I'm sure also helped shape some of your advocacy, some of that framework that you're seeing.

Nanette Opperman ([42:25](#)):

Yes. Yes.

Raquel Rosa ([42:27](#)):

What gaps there are.

Nanette Opperman ([42:30](#)):

[00:42:30] Well, gaps. And then the other thing that I noticed is when I was working there, I was taking on their problems. I was feeling for them. And then I finally said to myself, "Nanette, you have to be an adult here. Stop being their friend and start stepping back."

([42:48](#)):

Because I think, and this may be as an advocate, you can be there for them, but you can't baby them. You know what I mean? You still have to do your job. [00:43:00] And it's not exactly the same in the advocacy as it was as a recreation therapist, because I'm trying to get them to meet their goals. But you just can't take on every emotional thing, I guess. You have to compartmentalize.

Raquel Rosa ([43:15](#)):

Well, and I think that goes back to being an advocate and being a self-advocate, that you've been in the space of both as yourself, self-advocating, but also working with other folks who have other support needs and all of that, that [00:43:30] you were helping facilitate their experience and also stepping back and saying, "All right, you're the leader. This is your life."

([43:39](#)):

And even with goals and all of those things, there are still people who can say, "Oh, I'd like to try it this way. I'd like to try that."

([43:48](#)):

And you're not saying, "No, it's the way [inaudible 00:43:51]"

Nanette Opperman ([43:50](#)):

Right.

Raquel Rosa ([43:52](#)):

Like, "This is it."

([43:52](#)):

So people still have flexibility and creativity, and for you to encourage that and say, "Hey, look, I get it. We have [00:44:00] similar experience."

([44:02](#)):

Yeah, I'm sure that that was also, again, you're on the time machine, "Hello, 1995, 1996, 1997." Yeah, I think that we don't know what's ahead and what is going to come our way and what helps us become who we are.

([44:20](#)):

So switching gears real quick, another idea for outreach and engagement is doing just this, having a conversation, [00:44:30] a videotape recorded conversation where you can interview people who are as adults talking with their younger selves. This will help provide advice and perspective for young people today and the people in their lives. It helps them prepare for opportunities like giving testimony to legislators, council members, other elected people. And I think it also helps foster high expectations. Because [00:45:00] unfortunately, the world does not frame disability as a high expectation experience.

([45:08](#)):

And so, here you're seeing a woman who is married, independent, published author, a career person, you're seeing a fully formed life, and she did this with her own grit and her own tenacity. And this can be anybody's experience. We just have to step back. We have to let [00:45:30] people lead their own desires. And we provide support, we provide advice as asked, but there are lots of ways that we can help throw a baton to the younger generations. I think some of these conversations and lessons learned and encouragement from adulthood is another way of making that happen.

([45:50](#)):

All right, so Nanette, what advice do you have for us collectively as advocates and for individual people? [00:46:00] And then the second part of the question is, how can we create space for lived experience?

Nanette Opperman ([46:07](#)):

Well, the biggest one you already mentioned is listen. So listen to the people that you're trying to help. The other thing that I think is important is that you promote them becoming independent. What they can do, they do, and you support only when needed, and you find a way for them to do the things that they can't do. The [00:46:30] more I do and the longer I do it, the better off I'll be. Especially, I mean, obviously learning that from the hospital experience. If I do not keep walking, I will lose a lot. If I do not keep putting on my shoes or whatever I have trouble doing, I will lose it. Religious or not, if you teach a person how to fish, they'll live a lot longer than feeding them.

Raquel Rosa ([46:59](#)):

That's right.

Nanette Opperman ([46:59](#)):

Another aspect [00:47:00] that I thought was interesting is you're not your client's friend. That's come up on Instagram and other sites. I'm not saying that you can't be friendly, but you come and go, whereas in theory, their friends will stay or their family members, and so you want to promote the people that are going to be around constantly. That doesn't mean you can't be friendly. They need consistency, because consistency [00:47:30] is key to a lot of things.

([47:35](#)):

Another thing that I wanted to point out is parents are important when you're young because they see things that are important like therapy. I hated therapy, hated it. Nobody else had to do therapy, but I did, and I hated that. I had PT three times a week and OT twice. I was always doing therapy after school and I hated [00:48:00] it. And my mother's reasons for doing that may have been different, but they helped me in the end, because the longer I had therapy, the more agile I was, the stronger I was, the more I moved.

([48:14](#)):

When I went off to college and I had it less, my lungs decreased capacity, the whole nine yards, because I was always in my chair. Because I was trying to get from here to there and everywhere, [00:48:30] and I barely walked at all, and it showed. I mean, it had real ramifications. So my mother was really quite wise with therapy. So yes, there's self-advocacy and yes, you want to be your person, but when you're young, it does behoove you to listen to your parents and to take their advice. Okay, so I would say work with both and educate the parents as much as the kids, right?

Raquel Rosa ([49:00](#)):

[00:49:00] Yeah.

Nanette Opperman ([49:02](#)):

Because some disabilities will not benefit necessarily a whole lot from therapy, because they are what they are. They're not going to improve or whatever. Although, I am a firm believer that some kind of yoga or stretching of some sort can benefit anybody. But some things are just not going to improve. So what do you want to spend your time on? Do you want to spend it on [00:49:30] your brain or do you want to spend it on therapy? You know what I mean? So you've got to pick your battles.

Raquel Rosa ([49:37](#)):

Yeah.

Nanette Opperman ([49:37](#)):

Creating space for lived experience. Like you said, these interviews, reading books that people have written so that you know a little bit more about your people. You could do Instagram, you could do Facebook, recreation therapy, doing things like that. I don't know if volunteering at places [00:50:00] like that or recommending those kinds of things. I did horseback riding because that's going to be fun and that's going to bring friendships and growth. Let's see.

Raquel Rosa ([50:12](#)):

No, you're doing great. I mean, I think what you're saying is that people should be opening up their own experiences to make space for lived experience with disability.

Nanette Opperman ([50:25](#)):

Yes.

Raquel Rosa ([50:26](#)):

And so this is something that anybody who knows me knows, especially [00:50:30] people who know me in this work, is it's really important that we are connected to people with disabilities in our lives, that it's not just a professional relationship. And I'm not saying that those are not valuable because they are, but I also think that the soft skills of approaching people and engaging with people comes from having natural relationships. So that's something that I think helps us develop those advocacy skills [00:51:00] in a different way. For Nanette, that was imposed upon her through her own lived experience. For me, it was imposed on me because I have a brother with a disability. And so as young people, Nanette and I were both exploring what that is in different ways. So we didn't really have a choice, but we still choose to be active and intentional about how we create space for what this-

Nanette Opperman ([51:29](#)):

It's interesting [00:51:30] that you brought that up because I was living it, but I will tell you this, a lot of people... I was reading Judy Heumann's book. She had a lot of people around her that had disabilities. I did not have that experience. I was always the only one, which didn't bother me at all, because I have this way of... I just assume when you're talking about somebody flying a kite, [00:52:00] I'm flying it, too. Sometimes we need to put ourselves in situations so that we can become familiar, like you were saying. And I'm learning all of that through Instagram. It's like, "Oh, there's a lot of people out there. And oh, you have this and you have that." And I had to put myself in it because geography is going to keep us apart. And then, [00:52:30] you add in not being able to get places because of cars and buses and-

Raquel Rosa ([52:35](#)):

You're right. I don't know if they call it this anymore. I'm sure I'm dating ourselves, but I don't care. They used to call the internet the information highway. And so, that's a way of being connected on a larger scale that you're talking about. Even though Judy is no longer with us, we still see so much of her contributions to this work.

Nanette Opperman ([52:56](#)):

Oh, yeah.

Raquel Rosa ([52:57](#)):

I mean, I was fortunate to have met her a couple [00:53:00] of times, and I mean the first time I almost passed out. But when you're talking about somebody who was such a legend and really the godmother of disability rights, we know that together we can do a lot of things. And it really is about being open and being willing to be part of what this is, linking arms with your friends and neighbors who have disabilities and who don't. And so, yes, and some of that is even online. It could be in real [00:53:30] life. It could be... I can just jump on a train and be at Nanette's in two hours or two and a half, something like that.

Nanette Opperman (53:37):

Yes.

Raquel Rosa (53:38):

Or I could see people online. And so that really just helped, I think, broadens our perspectives and gives us another sense of community.

(53:47):

All right, self-assessment time. So P&A friends, how does your P&A demonstrate allyship and solidarity? This is kind of like an audit. What [00:54:00] expectations do, when I say my, we're saying about you yourselves, do your family, friends, and colleagues with disabilities have of you? How are you showing up? Are you mindful of disability tropes? So there are a lot of those in media. Some of them are less savory than I choose to share here, but we want to make sure that we're not playing to stereotypes, that we're not playing into hierarchies [00:54:30] and other things that really put people with disabilities in a different space than the non-disability experience. So being mindful of tropes, labels. And then how can your P&A help better amplify stories of lived experience?

(54:43):

So I think this is a really great brainstorming opportunity for all of you. And it doesn't have to just be comms people. This could be people in your legal side, in your lay advocacy side, in your intake. You're going to get a lot of experiences and a lot of [00:55:00] advice. So I would strongly recommend that. Talk to your family advisory council members. That's another place where you can be getting lived experience. Please tap into all of those pools of folks and those minds and those experiences. So that really, I think, will help flesh out a really cool approach to developing new content.

(55:22):

All right. So Nanette was talking about reading Judy Heumann's books. We've got a list, quite a list, and I'm going to do this quickly. [00:55:30] You can look at this later. You can hit pause. This is on the learning management portal. Elevate for my P&A friends, you can collect this there. This is just a nice long list of books that are written and edited by people with disabilities that really just help give you those stories, give you those perspectives, give you other names to tap into. Some of these folks are [00:56:00] independent contractors or consultants, I mean, and they can go talk to your P&A, you have to pay them, but these are folks who are happy to do presentations, to be at conferences, people who can do webinars with you. You should check them out. I'm not going to give you direct recommendations, but definitely know that there are so many people out there with just a variety of experiences, a variety of advice, and truly lived experiences at the core of this.

(56:28):

So we are wrapping [00:56:30] up. Thank you very much. You have hung out with us for a little over an hour, I think, and I've got our contact information here. Nanette, this is your Instagram. They can just click and go right to your Instagram page. They can see all the content you post almost every day.

Nanette Opperman ([56:47](#)):

I try.

Raquel Rosa ([56:48](#)):

I love the videos. I love the posts. And all of you can check her out, too. I mean, I'm not saying this just because she's my friend. I'm saying it because it's good stuff. If you have questions for me, you could [00:57:00] just hit me up on email. Thank you for joining us. Nanette, thank you so much. I just [inaudible 00:57:07].

Nanette Opperman ([57:07](#)):

Thanks for having me.

Raquel Rosa ([57:08](#)):

And I mean, I'm going to do my best to not cry because I love this. So this is a great experience. I'm so glad that we can do this together. Thank you. Thank you. Friends, thank you so much. We'll talk soon. Take care of each other. Take care of yourselves. Okay.