

## Neurodiversity Libraries, activism & community-building: Interview with Lei Wiley Mydske

May 28, 2022

[Intro music: Jazzy synth pop music]

**Anne:** Welcome to the *Noncompliant* podcast. I'm your host Anne Borden King. *Noncompliant* is on a bit of a hiatus but I've hopped out of hiatus to do one show today. Today I'm speaking with Lei Wiley Mydske. Lei is a writer and artist, creator of the [Neurodivergent Narwhals](#), Co-director of [NeurodiversityLibrary.org](#) and founder of the Neurodiversity Library Movement. They are the Community Outreach Coordinator at the Autistic Women and Non-Binary Network and a contributor to the group's anthology, *Sincerely, your autistic child*.

Lei has presented at a range of conferences and gatherings on autistic advocacy, and Neurodiversity Libraries in the community. You can find Lei's work on their library website which is [NeurodiversityLibrary.org](#), and on other links that we'll include on the podcast blog. Lei is the co-owner of Stanwood Tattoo company in Stanwood, Washington which also hosts a Neurodiversity Library.

We're going to talk today about their library initiatives, the Narwhals Autistic Community and more.

Lei, welcome to the show!

**Lei:** Thank you. Thank you for having me.

**Anne:** How did you first get involved in autistic advocacy.

**Lei:** I'm a parent and my child is autistic; they were actually diagnosed before I was, and during the process of having them get a professional diagnosis, it was mentioned to me that I might also want to seek out a diagnosis. So, I did...and actually it was the recommendation of a counsellor at my child's school that I check out blogs by autistic people. One of the first ones I read was [Radical Neurodivergence Speaking](#), and that really got me interested in advocacy and activism. I started making connections in the community, reading a lot of blogs by autistic people and learning a lot for a few years before I became involved myself.

**Anne:** Wow! Let's talk about the Narwhal project, because that was one of your early projects – it's still ongoing. The Narwhals are these amazing graphics that educate about autism and promote understanding. They're on social media and there's also a series of free downloadable

books and posters. They're for kids and adults and parents and they're so artistic and wonderful and accessible and eloquent.

I'm going to list out just a few of the titles of the Narwhal books. One is *Why is everything so weird, a Covid social story*; *Everyone Communicates* which is about AAC; *Inclusion in the Classroom*; *The Language of Neurodiversity*; *Whole Body Understanding...* and these are just some of the titles that are available on [NeurodiversityLibrary.org](https://NeurodiversityLibrary.org).

My first question I think is why did you choose the narwhal for your books?

**Lei:** So, the narwhal... I just really like narwhals and... (laughter)

**Anne:** (Laughter)

**Lei:** ...and I thought that *Neurodivergent Narwhals* sounded really nice together, so that's pretty much the reason why I chose narwhals, plus they're really cute and I like them a lot and they're interesting and they're different. Like, when I first started making the graphics and the little comics, people actually thought I made up the creature...

**Anne:** (Laughter)

**Lei:** And I'd go, "It's a real thing. There are actually narwhals that exist. They don't look like little like happy balloon animals..." (laughter). So yeah, I wanted to find a way that was kind of fun and to take concepts like the **neurodiversity paradigm** that were really inaccessible to a lot of people and make them more accessible and fun and kind of easy to understand. And I just thought the narwhals fit with that.

**Anne:** Yeah, I mean that's one of the amazing things about the books is that there are all these concepts that are talked about in academia and research, but so much of the discussion – until really recent times through work like yours – has been very inaccessible and also just not *enjoyable* to read about and understand. Neurodiversity is a wonderful, enjoyable thing and these books really reflect that as well.

What has been the community response to the Narwhal Project?

**Lei:** People seem to really like them. Sometimes, I'll have people share them with me not realizing that I'm the creator of them. Like asking me what I think of it! And it's been really

positive. I've actually sold some curriculum materials to different school districts in the United States and Canada. Some therapists and therapy practices have purchased them and even there was a television show that reached out to me and wanted to buy some posters for a set design for a bedroom of a character who was autistic.

I'm still working on a book that I hope to self-publish...it's a little bit hard because it's just me... but hopefully, I'll be able to finish it soon. I think that the response has been pretty positive.

**Anne:** Wow, that's amazing! What about the schools? Were they using them to educate students or...

**Lei:** I think they were using it for students and for teachers, and just as classroom posters.

**Anne:** Wow, and so it's taking off and it's still going. It's amazing. You also founded the Neurodiversity Library Project. What is a Neurodiversity Library?

**Lei:** A **Neurodiversity Library** is just like a curated collection of books, information and resources that reflect the values of the neurodiversity paradigm, **autism acceptance** and **disability justice**. [The libraries] can look very different from one another because a big goal of mine with the project is to make it accessible, not just for people to get the information, but for people who are running it to make it work in the way that works best for them.

My library is an actual little bookmobile that's in my tattoo shop, but there are some people who just collect funds and donate books to their local library, and some people have little free libraries. And there's other people who just bring books to play groups. One library could look very different from another one.

**Anne:** That's so cool. What was your inspiration to do the project?

**Lei:** A big inspiration was just the lack of available resources in my community. There were resources about autism, but none of them were from **actually autistic** people or other disabled people...and what was available was not like neurodiversity or disability justice-informed. I knew that there were resources out there, but people just weren't getting them unless you went looking for them specifically.

A big inspiration for me was also my father, who I strongly suspect was autistic. [He] was definitely neurodivergent and he had some physical disabilities and he was a grassroots community activist. He worked a lot with people on poverty and doing food distribution

programs and free meals in our community and he was extremely passionate about justice and using what he had to help other people. My family was...we were always talking about social issues and my dad taught me things about feminism and socialism and racial justice. I know he didn't have an easy life, but he absolutely believed that part of why he was here was to make the world a better place than it was before. So, I feel like the library is kind of honouring my dad's legacy.

**Anne:** Wow, is that... Did you name the library after him?

**Lei:** Yes, I did.

**Anne:** The Ed Wiley...

**Lei:** ...Autism Acceptance Library.

**Anne:** So you started your library and then how did it spread and grow beyond that?

**Lei:** When I started a library, I really didn't realize that it would grow, but a few weeks after I kind of created mine, I got an email from **Lana Thomas**. We did not know each other at the time, but we actually have become really close friends. She wanted to start a library of her own in California where she lived at the time. We just exchanged emails and I tried to answer any questions that she had and when she created her library. We worked together to create a resource for other people who might be interested in creating their own.

We made a PowerPoint on how to [create a neurodiversity library], we went to conferences and presented it and we created a Facebook group to connect people who are interested in starting neurodiversity libraries.

**Anne:** When was all this happening or starting up?

**Lei:** It was about 2014.

**Anne:** Who uses your library...or the Neurodiversity Libraries in general?

**Lei:** A lot of autistic people use the library, especially newly-diagnosed people who are looking for information, and just wanting to not feel alone. Parents, teachers, professionals, they all come to the library - anyone who is interested in learning more. Especially since I have it in my shop now, a lot of people who wouldn't otherwise check it out just see it and want to find information and really enjoy it.

**Anne:** Wow, what kind of feedback do you get from parents?

**Lei:** it depends (laughter)

**Anne:** (laughter)

**Lei:** A lot of the information that I present is very different from what they've been told. So, if they're open to learning from autistic people I've heard very positive feedback. But if they're more resistant to the ideas of neurodiversity and disability justice then I kind of get a little bit more push back.

**Anne:** Yeah. From autistic people, it must be such a just a generally positive response.

**Lei:** I think it is. Especially since it's been in my shop, people don't expect it to be here and then they tell me that they're autistic or their child is autistic. I've had more than one person like tell me that they're autistic after seeing the library and reading some of the information. Just making connections and even having like email relationships with some people who want to find out more. And I always welcome people, especially on our slow days, to just come to the library and hang out, and that usually is a pretty fun time.

[10:07]

**Anne:** It must be like a safe space, especially for people who might have stress in other parts of their life or are facing ableism in other parts of their life to just be in a place that's so affirming.

**Lei:** Mm-hmm. That's what I hope, and I hope that that continues too.

**Anne:** It seems like the libraries are an opportunity not just to lend out books but – and I should say we're starting one here so I'm really looking into this a lot -- it's more than just lending books, it seems like it's about building community and helping people in their lives. Is that

something that you see happening in the libraries?

**Lei:** I do see that. I know from my own experience. I work very closely with our local community resource centre. They do a lot of outreach too and we kind of collaborate. We do monthly events called Community Conversations and we talk about autism and disability. Sometimes we'll have guests talking about like equity and diversity and we're all people who are local in my community. Just like giving them a platform and having these conversations I think is really important to our community especially where I live. It's a very small town and some of the ideas are not as welcome here.

I see that it's rapidly changing and I love that. And I also collaborate Autism Acceptance month events with our resource centre and also with AWN – the Autistic Women and Nonbinary network. They are the primary funders of the library as well. And one thing that we're doing that I'm really excited about is where I live (Stanwood, Washington) is having its first ever Pride event in June and my library has a tent there. It's just going to be a sensory break station for anyone who wants to go to Pride but [Pride] might be a little overwhelming. They can come and sit in our tent and read some books, play with some stim toys and just relax for a little bit away from the noise.

**Anne:** Wow, that's great! There's so much overlap in the queer community and the autistic community that there'll just be tonnes of people who will need something like that. Can you give some examples of how people are creating their libraries to fit the needs of their communities and how their communities look?

**Lei:** One of the libraries was called L.A. Neurodiversity. Los Angeles is a huge city so what they did was raise money and donated books to their local library because they felt that would have the most impact and also be more accessible for them.

There's a Neurodiversity Library in Northern Virginia that is run by a parent who is also really involved in talking about gentle parenting and peaceful parenting of autistic children. What they do is they bring books to playgroups and parks and just meet with parents and loan out the books. I mean, really there's so many ways to do it.

In Australia there's Neurodiversity Hub, which has grown beyond just a library and now they're doing a lot of classes and meetings and support groups for people who are autistic or LGBTQ. So, there's really so many ways to do it.

**Anne:** Yeah, and it's changed over time too. I would guess like probably some public libraries are starting to have somewhat of a collection at least be more open to having a collection. Do people relate with their public libraries around this or does it tend to be sort of independent of the [public] library?

**Lei:** I believe that Paper Boat Autism Library in Mississippi had experience working in the library and that's what inspired them to do their Neurodiversity Library. I actually went to a conference a few years ago that was a librarian conference and it was called "Targeting Autism"; they wanted to learn how to bring materials into the library that were more inclusive, so I went there and I met a lot of librarians there who are like official librarians who were really excited. Some of them have emailed me and some of them have joined our neurodiversity group. They want to find ways to bring books into their library that celebrate autistic people.

**Anne:** Yeah, and that's such a change.

**Lei:** Yeah.

**Anne:** That's such a change... you can easily walk into a library, even today but especially a couple years ago (and of course online and before initiatives like yours) you could just be searching for information about autism and the first things that would pop up on the bookshelves of the library or online are just these terrible, terrible stories that don't reflect real life.

**Lei:** Yeah. When I started the library I actually did go to my local public library and looked for books on autism. They had *Thinking in Pictures* by **Temple Grandin** and then they had some books by professionals, but they also had books by parents and one of the books that they had was called *I Would Rather be Engulfed in Flames* and it was a parent writing about parenting her autistic child and...

**Anne:** Oh my God.

**Lei:** .... so that was a big inspiration to start the Neurodiversity Library, too.

**Anne:** Since you started the libraries, what's changed in how people respond to it, or just generally within the world of the parents and the families?

**Lei:** When I started the library, I feel like I was criticized a lot for pushing back on things like ABA and organizations like Autism Speaks. In the last few years, I'm seeing more and more people coming to me and already recognizing things that are problematic. And I'm seeing more parents who are willing to listen to autistic adults than before – even listening to autistic adults who they might not have the easiest time listening to, which is most important I think.

**Anne:** What do you think needs to happen to really bring people from the margin to the centre that are continually marginalized--within also our own activist and advocacy spaces?

**Lei:** I would say to learn about disability justice...like to *really* learn about that before you start a library because it's really important to be informed about what that actually means and to also not be afraid to **pass the mic** because you don't always need to be the person centred.

**Anne:** Mm-hmm.

**Lei:** ... and one of the things I'm trying to do when I have the community conversation events with my community resource centre is to make sure that when I have the events that they are platforming people who usually don't get a platform in my community.

**Anne:** Let's say someone wants to start a Neurodiversity Library from scratch in their community, what are some of the first steps to start to build one?

**Lei:** Learning is a big step and also finding out what the needs are in your community and to make sure that you don't over-extend yourself and it's something that you can do and know that you might need to take breaks and it might not happen as fast as you want it to. It took me a long time to get to a place where I was really comfortable and I felt like I had the routine for doing my library events and having an inclusive library.

But I really think the big thing was making the connections in my community. And not just in my local community which is extremely important but also with the autistic community. I collaborate a lot with the AWN network. I've had some collaborations with ASAN in the past where they've donated books to me and just finding the people who can help you.

**Anne:** How would someone overextend themselves? Like trying to do too much too fast or...?

**Lei:** Yes, and I've done that in the past where I've tried to do too much too fast, and now I take summers off! But I did, I tried to do so much of everything by myself and it really was not sustainable, so I slowed down a lot. Like, in the past I'd bring my entire library in totes to my community resource centre which was really fun and I liked it a lot but over... it just got to be more of a job because I had to carry the books back and forth and then I had to do a lot of advertising like, "Please come and see me" ...

**Anne:** Right.

**Lei:** ...and it was a lot of work. It was worth it, but then when we opened our tattoo shop I said, "I can have it here while I'm already here working," and it's still a space where people in the community can come and check it out and it's not quite as much work for me. And I can still maintain my relationship with my resource centre locally and do special events once a month, or when I'm able to.

**Anne:** Yeah. I don't know if it's an autistic thing or what it is – this kind of idea, I have it a lot and it's always a terrible idea but I continue to have it and I fight that,... that "I'll just do it myself..."

**Lei:** Mm-hmm, yeah.

[19:35]

**Anne:** ...Like, *why* am I saying this? "I'll just do it myself." There are so many things wrong with that way of doing things. I don't know if it maybe comes from parenting experience too or something but...

I was at a meeting of a disability coalition--it's a bunch of different disability- related groups in Ontario--and we have these meetings every month or so and we got to talking about some really just terribly grim legislation that they're talking about in Canada around assisted dying and it's very problematic. We were all talking about how to get the message out about how troubling it is. And a lot of the work in this space is often about trying to inform [the public] about things that are really going wrong. Somebody said, "what are we going to do to help people *in* our community?" We're talking about how we want to get the message out to the broader community that the proposed legislation is bad, but how are we going to help people in our community like, not just become totally despairing about this...and bring people joy and have people feel hope, right?

Like you, I grew up adjacent to activism and sort of came of age with like a megaphone in my hand and rallies and...*this is what we do on Friday night*, right? And in that time, at least where I lived (in Madison, Wisconsin) it was pretty much like, you just do everything you can to save the world until you can't do anything anymore and then you just burn out. And then you disappear and nobody sees you again for a really long time and maybe you bought a house in the country or something. And there was no sense of like, self-care or anything like that. It was pressure, pressure, pressure: 'Are you going to be there? Are you going to do it?'

And the thing is that the problems that we're dealing with in the world are so big that fixing them is like a multi-generational process and so now I'm trying to just take a breath and say like, I'm going to do what I can do but this is a really long struggle, right? And 50 percent as an activist maybe is helping people be okay...helping the people doing the work be okay.

**Lei:** Yes. I was never like a 'group project' type of person but I have learned over the years that that's really what I need and what everybody needs, because you need people to do the type of activism that's bigger picture and even policy work...and then you need people to like, take care of people locally. You need all of it. And for some people, their strength is policy work. Mine is not. My strength is more like local community, very grass roots.

I also think that finding community is good because some people will give you ideas that you never thought of before, or you might give people ideas that they never thought of before. And I don't know, it's surprising to me being such a shy, quiet person, and very independent, like 'I'll do it myself,' to **find my community and know that I need them, and they need me too.**

**Anne:** We talked a little bit about how someone starts a library which is to have the idea, connect with people in the community and not bite off more than you can chew. There's also a Facebook group for Neurodiversity Librarians, is that right?

**Lei:** Yes, there is, and...I am not the best Facebook group moderator, I'll say that now, but I'm trying to be more active in this one and one of the reasons is that I started doing Zoom meetings with the Neurodiversity Librarians; they are a little more accessible for me. Facebook groups you can get kind of bogged down in the comments and it's just a little bit confusing sometimes for me. But there is a group and it is very helpful, and we like give each other advice and talk about different books and different projects that people are doing. So, yes.

**Anne:** Yeah, it's an amazing group. I attended my first Zoom a while ago and what I thought was really great was also the way it's building connections *across* different communities, really around the world. So, we can find each other too, as part of something broader.

**Lei:** Yeah, and that's one [reason] why I like doing the meetings. One of my favourite parts of activism is just finding connections with people. I feel like it's really important, especially if you're someone like me. I live in a very rural area and it's a little isolated, and sometimes it feels like you're the only one who knows anything about neurodiversity or disability justice and it can be pretty isolating. So, it's nice to connect with other people who are doing the same kind of work to try to educate their communities too.

**Anne:** Yeah, it's really, really positive. I was wondering about the future. Let's say 2022–2023, what does that look like for you in terms of the libraries and the narwhals and everything else that you're doing?

**Lei:** Well, I hope to finish my book. It's been a long process and I'm teaching myself along the way. So, I hope to finish it this year. We'll see if that happens. I hope to have more meetings on Zoom with Neurodiversity Librarians so we can collaborate with each other and learn from each other.

I know one thing that's coming up is the Pride event in Stanwood that I'm so excited about – to be able to meet people in my community at an event that's just a celebration. So, I feel like that is a really positive impact that my library will have. And, I want to continue my community conversations, where we bring people to the library, and to the community to talk about important topics.

And I will continue working together with AWN as well and I'm really excited about some of the projects I'm working with them also. We're just exploring a couple options to kind of bring our liberating webinars to other avenues. A thing I want to do is working with different autistic bloggers, like Morénike Giwa Onaiwu and I did a series of webinars with Jules from Autistic Typing and I finished one several months ago with Ashia Ray who does Raising Luminaries that will be edited and put out soon. It's about ableism and using children's literature to fight back against ableism.

**Anne:** Well, we're going to include links to Lei's projects and other projects related to the Neurodiversity Library Project, and I just want to say thanks again Lei, for being on the podcast. It was really, really interesting. Thank you.

**Lei:** Thank you so much for having me.

[Jazzy synth pop music]

**Anne:** We were speaking with Lei Wiley Mydske. They spoke to us from Stanwood, Washington.

You've been listening to *Noncompliant: The Podcast*. I'm your host, Anne Borden King. *Noncompliant* is recorded at MCS Studios in Toronto. This episode was engineered by Francois Heroux and transcribed by Julie-Ann Lee. Thanks to Francois. It's his last episode engineering; thank you for so many great episodes. And thanks also to Julie-Ann Lee for the amazing transcription, and to everyone involved and everyone for listening.

[music fades to quiet]

\* We DO NOT recommend this book. For the sake of accuracy the title is, *I Wish I Were Engulfed in Flames: My Insane Life Raising Two Boys with Autism*