

## [“Disrupting the Autism Services Market”](#): Interview with Foundations for Divergent Minds founder Oswin Latimer

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Transcribed by Julie Ann Lee

(Theme song - soft piano music)

**Anne: Oswin Latimer** is an Indigenous, non-binary, Autistic adult, parent to 3 neurodivergent children and a disability advocate. Oswin is a founder of **Foundations for Divergent Minds**, which we will focus on in this episode. Prior to founding Foundations for Divergent Minds, Oswin was Director of Community Engagement with the Autistic Self Advocacy Network (ASAN) and in addition to activist and education projects there, they represented the autistic community to policymakers in the US Department of Labor, Education, Personnel Management and others.

After leaving ASAN, Oswin spent several years as a disability consultant, advising parents on ways to set up their homes and create individualized education plans that better met their children’s needs. They also compiled and edited *Navigating College: A Handbook on Self Advocacy Written for Autistic Students from Autistic Adults*, among other projects.

I am so glad to have Oswin on the show today.

**Oswin:** Thank you.

**Anne:** So, how did you come up with the idea for Foundations for Divergent Minds?

**Oswin:** Many years ago – 11 years ago, I was diagnosed autistic through a series of court cases that was not good. But shortly thereafter, I gained a really intense interest on how the way I was parenting was different from what I was seeing with **\*allistic** parents with their autistic kids. So, as I started to really dig into it, I thought there has to be a way for me to present this information to the masses and for many years I kept on thinking, ‘I’ll write a book. I’ll write a book.’ I never wrote a book (laughs)...

**Anne:** Hmm.

**Oswin:** ... when I was working at ASAN in DC a few years ago, I met a woman, Cecilia Breinbower, she was the Executive Director of ICDL which is the Floortime organization. After I left ASAN and as I was working on a presentation she’s like, ‘Do you know, this is really good! We should really sit down and come up with a way to make this into something that we can train people on.’

**Anne:** Mm-hmm.

**Oswin:** Because it was all around the way that our perceptions and our language affects the way we see our kids....

**Anne:** Mm-hmm.

**Oswin:** ...and then affects the way that we treat them. Not in a treatment sense, just like how we actually just talk to and interact with our kids.

**Anne:** Right, right. Often overlooked.

**Oswin:** And so she really encouraged me to sit down and actually make this into something that we could teach to professionals. We were originally just going to [create materials for] professionals, and no parent piece because that's where her connections lie. But after a bit, I realized this should be more than that...and when we launched, it was with an idea of providing education to everyone.

**Anne:** Yeah.

**Oswin:** Because even autistic parents tend to try and cobble this together based off of what they know of themselves. We didn't want to make this be specific about any particular group of people, it needed to be for everyone because everyone needs to change their ways of interacting with autistic kids and other neurodivergent kids.

**Anne:** Mm-hmm.

So, then you decided to launch the program. I looked at your program and the thing that jumps out at me right away from your materials (and maybe that's going back to these earlier conversations in the creation of the program)...what jumps out to me right away when looking at Foundations for Divergent Minds is **quality of life** and the fact that you include quality of life and make that a central aspect – because when we look at older models of service, quality of life often isn't really considered in their outcomes and measures. Like, with ABA their outcomes tend to be all about *compliance*, and they don't really look at something like quality of life and **satisfaction**. So, tell me about that difference. How does quality of life consideration play a role in your program?

**Oswin:** It is really the whole basis of it because as I look at everything that I've ever been given for my own kids (and my kids are also autistic) I always see this 'how are we going to make them look [a certain way]' or whatever. But never does it come out that people are looking for **happiness** and it's one of the first things that most people... Most professionals say to me when they end up meeting my kids and interacting with my kids is how happy they are. And like, *why shouldn't they be happy?* (laughs)

[5:23]

**Anne:** (laughs)

**Oswin:** But it's always like that key, central thing that people say is 'your kids are just so happy.' Yes, they are because we don't try to change them. And I want people to understand that – that kids can progress and be happy without having to change who they are fundamentally.

**Anne:** Mm-hmm.

**Oswin:** And just that information – and there's actually some research behind it--that if a parent just knows why a kid is doing what they're doing, that you see a decrease in 'behaviours' and you see an increase in satisfaction for the parent and for the child. I really wanted to make sure that people understood that that should be the core, because if somebody's happy of course they're not going to have meltdowns all day. (laughs)

**Anne:** Right, right.

**Oswin:** If they're happy, of course their sensory systems are going to be regulated. And sometimes their sensory systems being regulated is going to make them happy! Like it's not just one way or the other. It's trying to help a person really get to where they are comfortable with themselves. Because when they are comfortable with themselves, then they can learn.

**Anne:** Right, I mean the fact that you're standing out from the crowd in some ways, by saying that really says a lot also about how our society has looked at disability and particularly autism and the shift that's finally, I hope, is really happening.

I wanted to talk about the 5 areas and what that would look like – the 5 areas you focus on right now in the program is **Sensory Regulation; Executive Functioning; Communication; Socialization;** and **Emotional Regulation.** So, how would people be putting the ideals of the program into practice, for example, in their home?

**Oswin:** Well, that's a great question. Our parent training is specifically designed to help a family set up their home in these 5 areas. Because that's kind of key...because I believe that a person when they're at home is when they should be the least disabled possible, because that is *their* environment, right?

**Anne:** Mm-hmm.

**Oswin:** So, we look at helping parents come up with inventorying their surroundings for the **sensory information.** So, does your child need a lot of visual information to understand what's going on? Do they need to have a less cluttered environment and maybe things put away so they can regulate their system? Or maybe they have *too much* information – or they need to see what they have in order to interact with their environment? Right?

**Anne:** Right.

**Oswin:** Sometimes it will go into a person's room – depending on the family because obviously if you have more than one autistic person in the family, you're going to want to set up different areas for people to go and cope- or that's made for their needs. But, for other people it might be the whole house where you try to minimize all the sounds.

**Anne:** Mm-hmm.

**Oswin:** Maybe keep all your windows open so you get that sunlight in? With the **Executive Functioning,** maybe you have a lot of timers- maybe you have a lot of technology in your home that tells you when to do things? Have things set up so you can visually see without having to worry about if you can communicate what's going on, so you can set up chore charts or you can set up visuals around your house for order of things. Like, in my kids' bathroom we have a laminated sheet of paper with the steps to take a shower.

**Anne:** Mm-hmm.

**Oswin:** It's just posted in the bathroom, so they don't even have to think about what that process is. It is one of those things to help the 1. Destigmatize having those kinds of things just having them out is destigmatizing in and of itself. But also, just knowing that you don't have to worry about the "simple processes" that are actually really, really in depth.

**Anne:** Yep.

**Oswin:** That you have a lot of steps to do for each of those things.

**Anne:** Mm-hmm.

[9:55]

**Oswin:** For Communication you may have AAC around your house even if everyone is speaking. Our household relies heavily on texting even in the same room. (laughs)

**Anne:** (laughs)

**Oswin:** Because this is what we like to do. We've really focussed in on making sure when we socialize together, we do it in a way that is really that corresponds to what everyone's shared interests are, rather than trying to force people to watch a movie that they don't like.

**Anne:** Mm-hmm.

**Oswin:** We're making sure that we are keeping in mind what everyone needs in our home. And so, this is what it will look like for other people's homes so that we can really help them come up with that. And what I found is that we can have all these and the **Emotional Regulation** piece automatically, you don't need to have as much energy put into that because your life is not chaotic and your life is not confusing if you're not *constantly processing all this other information* then your emotions, then you can kind of feel them a little bit more easily, because your brain kind of focuses. [It] doesn't have to focus so much of its energy to the other things. And so then you can start to recognize that minimizing your communication helps you regulate your emotions. Working with your sensory system...really trying to help to minimize what it is that's making your emotions go haywire in the first place.

**Anne:** Yeah. Wow, that's really, really interesting. You were talking about communication a minute ago. **Communication** is one of the biggest areas where the old and the new approaches are so vastly different....the new approaches are about embracing AAC for example. So I'll talk in a minute about AAC. AAC means **Adaptive or Augmentative Communication**. Sometimes it's called **Augmentative or Alternative Communication** as well and what that means is almost any device or method that is not spoken speech. It could be a laptop app, it could be a piece of paper and a pen, or it can be any number of different platforms or ways of speaking that are not verbal.

For non-speaking students, AAC is essential and it can literally be a lifesaver. But we still have schools for example, without access to real AAC for students ...or making these kind of rudimentary PECs picture boards available to non-verbal students. I'm wondering what kind of strategies for Foundations for Divergent Minds are you offering around AAC?

**Oswin:** It's one of the things that we are really keen on is that we want providers and teachers to *ask for AAC from the start* whether or not a person is speaking.

**Anne:** Hmm.

**Oswin:** Because one of the things we know from a lot of anecdotal evidence from autistic people is that we sometimes feel like our words are not coming out nearly as nicely when we speak as we were able to type.

**Anne:** Mm-hmm.

**Oswin:** Just based off of years of talking about it, we all know that we just type so much better than we speak... (laughs)

**Anne:** (laughs)

**Oswin:** ...and because of this I really try to get people to recognize that just because somebody is speaking doesn't mean that they don't need other forms of communication to get what they're trying to say out.

**Anne:** Mm-hmm.

**Oswin:** So that's one. Two: a lot of AAC relies heavily on ABA.

**Anne:** Hmm.

**Oswin:** And I really, really hate that because there's a lot of hand-over-hand action going on in AAC sessions.

**Anne:** Right.

**Oswin:** Just trying to get people to choose the word that they think they're meaning, so I really encourage a lot of **hand-under-hand**: offering your hand to go underneath the other person's hand to kind of guide and direct to where it's supposed to go. We also really heavily feel that **Rapid Prompt Method** and **Facilitated Communication**...Facilitated Communication as much as I know that people want to pretend like it doesn't work, I know too many people that are FC and RPM users

**Anne:** Yeah.

**Oswin:** That I know communicate and communicate very, very differently than than their support person.

**Anne:** Right.

[14:57]

**Oswin:** Like, I just met too many people... there's no way that I would not believe that those people are communicating what they're communicating because I just know them too well. (laughs)

**Anne:** (laughs)

**Oswin:** So, we really recommend having those. Because it's not like it's any different from any other communication method. And I'm going to shift gears a tiny little bit to talk about my daughter who had apraxia and she's not autistic – poor little girl (laughs).

**Anne:** (laughs)

**Oswin:** And uh, one of the main methods of teaching a child with apraxia to speak is with motor prompts. You prompt different areas of the face and the throat to try to get those motor movements working to get the speech out.

**Anne:** Mm-hmm.

**Oswin:** And that's not all that different from the way that we use Facilitated Communication and Rapid Prompt Method. These are all guided motor prompts and the reason I am very, very much a proponent of it is because we know that there's a high rate of incidents of motor planning difficulties in non-speaking autistic people.

**Anne:** Yeah.

**Oswin:** I could get into theories on why I think that is but I'm not going to. If we can't get somebody to start speaking in any format – and when I say speaking I'm not talking about just verbal speech and what comes out of our mouth-- then when we need to have a lot of different methods to do that whether it's FC, whether it's RPM, whether it's a dedicated device. And I really like dedicated devices but some people can't do them and I'm not going to force somebody into that.

The biggest thing is knowing that children as young as two can use them, so when I talk to parents what I will typically try and get them to do first and foremost is if they can afford it get a little \$50 cheap android tablet, and there's a free AAC app they can put on that.... it helps a child get used to using that method of speaking early on.

**Anne:** Right.

**Oswin:** Even before anybody will approve – because nobody is going to approve a 2-year-old for an AAC device... for some really strange reason.

**Anne:** Mm-hmm.. Yet whether they use it or not, it will help with emotional regulation and communication, right?

**Oswin:** Right! It's a really simple app and it being a very simple device it's not robust like the really expensive ones, but it's available for at least more parents than [those who] currently have access to something for their kids.

**Anne:** The strange thing is I was talking to a social worker who oversees a lot of social workers and he said sometimes the parents *don't want* their children to have AAC, even when other people on the service team are showing them how valuable these tools can be. I'm wondering if you can share some of the methods that you have to teach about AAC... to go against this resistance so that people who want or need to use AAC will have access to it.

**Oswin:** One of the big things I try to do is bring in the fact that we know that **if somebody is going to speak, they're going to speak faster if they have access to AAC.**

**Anne:** Hmm.

**Oswin:** Like, just that one fact gets a lot of parents at least interested in using the device.

**Anne:** Mm-hmm.

**Oswin:** . The next is talking about the meltdowns, to be very blunt. Because a lot of parents feel that shame around the AAC device because they see their kid having to pull it out or carry it around – 'I don't really want my kid to be labelled and stigmatized.' But if their child is not able to communicate, they're going to be labeled and stigmatized anyway. And that's a lot more difficult to deal with in the moment.

**Anne:** Mm-hmm.

[19:59]

**Oswin:** The meltdown is really difficult in the moment and we all know that because Autism Speaks doesn't shut up about it. (laughs)

**Anne:** (laughs)

**Oswin:** But, really, if we can talk about the fact that we're giving this so you don't have to worry about the stigma of them melting down. They can communicate with you what needs to happen.

**Anne:** Interesting.

**Oswin:** Then more parents become a little bit more interested in just these little pieces here and there. There's still some parents that are just going to ignore everything you say, unfortunately. But, if you can just talk about those key things where they can start getting past this idea that 'oh, my kid is never going to speak' which may be true, but it doesn't matter if they can get this idea in their head that 'hey, if they're going to speak, I'm going to hear their voice sooner because I'm giving them this device.' ...I hate having to do that, but some parents need that and the kid definitely needs it.

**Anne:** The kid needs it. Yeah and that accessibility for the kids is everything.

**Oswin:** Right.

**Anne:** I'm so excited about your program because I see it as a market disrupter for autism services. Autism services is very much an industry and there're a lot of problems in that industry and it has got to be disrupted in my opinion.

So, what I like about yours is that you're offering a service informed by the population it serves, scalable to a spectrum of needs and environments, on an accessible and portable platform, and at a much lower cost than standard services, with no waitlists. You have satisfied users and it's effective, and it's so exciting. I want to ask you what the reception has been for it and I'm guessing that you're getting a lot of interest in your program. Is that right?

**Oswin:** We're getting a good amount of interest in our program. ...Parents are really interested in it because so many hear autistic adults say 'hey just listen to us and set your homes up and do *this* for your kids and everything's going to be great' but they have no idea what *this* is.

**Anne:** Right.

**Oswin:** Telling them, step by step what *this* is and helping them come up with the strategies [then] they come away and they feel good about what they've done. The providers are coming away and I am blown away by how much teachers, \*SLPs and \*OTs are all coming away with this 'you have fundamentally changed the way I do therapy.'

**Anne:** Wow!

**Oswin:** An, that is so amazing for me because that's the whole point. The whole point is to recognize that we have our own needs, we have our own development, and none of this means that we can't learn and need to be changed, you know?

**Anne:** Right.

**Oswin:** So I go back to Cecilia who encouraged me to create this in the first place and she took the course the first time around and said, 'you know 75 percent of what you said, I heard before and I already knew it. But, it's the 25 percent that I haven't and hadn't considered – that's what changes it.' Just those core things that because I know what the autistic experience is, and not just from my experience but informed by so many autistic people and I mean it's the community and we know what we need...

**Anne:** Right.

**Oswin:** ...even if nobody else is looking at it.

**Anne:** Yeah.

[24:47]

**Oswin:** So just the idea that we're able to encapsulate this idea into a training is 1. Amazing to me. I never thought I was going to do this. I never thought in my life I would do this. But, that people are so receptive to it and are encouraging others to take take the training, and really get invested in what we're doing enough to...I'm having people ask me, 'Hey what can we do to start offering this training locally to people? What can I do to start doing this for other people?' because they see such a difference in what this program does.

**Anne:** That's amazing! I think one of the things that you did in your program that made it so effective is that it is user friendly. That's the funny thing problem solving around issues in our community is that a lot of the solutions, a lot of the problem solving is actually really simple in the way that it needs to be approached. And the industry, the autism industry has a problem, with trying to make things sort of big in this technical mumbo-jumbo. The materials are kind of inaccessible, so many of the documents to guide parents and teachers...they're filled with jargon and then the 'experts' have to come in and oversee everything, *for a fee of course* to help the parents understand the materials and all of this kind of thing like it's a big deal.

But with your program it's a simple language so families and other users can start applying it and even replicate it with ease. Even teach other people all about it. It's such a change from the established system and I think it's a role model for others to follow because it's about accessibility for the families, for the children, for autistic people and it's also just generally about accessibility for everyone.

Could you talk a little bit about how and why you decided to present it in such an accessible way?

**Oswin:** I needed it to be accessible. (laughs)

**Anne:** (laughs)

**Oswin:** It's really that simple. Like, I go through and I read all of these things, and I've gotten to where I'm pretty good at reading the *professional-eze*. I can read it but when I'm trying to talk about it, I can't actually put it in those words because it's something I don't think that most people could possibly understand. And I want to make sure that when I present any information that I am going towards people that are going to use it every day and most people just don't have time to learn that amount of language – that amount of jargon. There's still some jargon in what we talk about because different

communities have different kinds of words they use but overall we try to make sure that anything that we do say has a definition because these are just standards for accessibility period.

And if we're talking about a program that's telling everyone to make *everything* accessible, we better be accessible ourselves. (laughs) I want to be accessible because it makes a big difference in everybody's lives. How many people- and I really hate going back to ABA, but how many people went to ABA because it was something that somebody could tell them to do because they couldn't understand what their- what was going on with their kid?

**Anne:** Yeah. Exactly.

**Oswin:** , I even saw this --way back when my kids were diagnosed – with RDI, which is (I don't even know if RDI is still around or not). But they had all this information but 'oh look, but you have to come pay for our class that's like \$3,000'.

**Anne:** Right.

**Oswin:** And then 'we'll hook you up with somebody that can tell you what you just learned which will pay even more'. And I was like: I don't want to do that. I want to be able to sit here with my kids and interact with them the way they need to be interacted with and live our lives. Who has the time for all that? No one has the energy for all that. I mean, I guess allistic people do. (laughs)

**Anne:** (laughs)

**Oswin:** But, I don't, and I don't really want to expect anyone else to have that kind of energy. I want people to be able to focus in on the things that will make the biggest impact for their kids.

**Anne:** Right, right. Then you can get on with living too. And I think that's one of the problems that people really get stopped from living their life and having fulfilled lives as families when they get caught up in this snowball-tornado of these types of services, and yours it's just very clean, and accessible, and clear, and it is focussed--like I said at the beginning--on fulfilment and happiness and enjoying your lives as families. The program for families and the program for school and professionals is very practical and again, it's focussed around quality of life, so I just love it.

I'm wondering what the next steps are for Foundations for Divergent Minds?

[30:13]

**Oswin:** Well, we are rolling out a level 2 training for professionals that have taken the level 1 training, so that they can then provide training for a 'train the trainer' kind of model so that they can train other people on how to use it. Because this was never meant to be this colossal 'we're going to make money.' No, this is about helping kids because I can't stand continuing to watch kids suffer...

**Anne:** Mm-hmm.

**Oswin:** ...at the hands of schools and therapists and everything. So that's our next step for providers. For parents we are looking at creating starter kits that you can even print out for free or we can assemble it and send it out to you for a cost that has a lot of the visuals that you want to have when your kid's first diagnosed and you're trying to find all this information.

**Anne:** Yeah.

**Oswin:** Just so they can start to help their kids make sense of what the world is. And routine cards and simple communication cards and some basic AAC so that when your kids are 18 months, 2 years, 3 years they have a way of communicating no matter where you're at. That's really the next step because we really want to have that- not just the education piece but really helping to create a way that you can easily support your kid in your home without a lot of legwork, because the legwork is what's so difficult.

**Anne:** Right. It's a toolkit approach – it's really interesting.

Well, I can't wait to see what [the future] brings for Foundations for Divergent Minds. It was such a pleasure to talk to you. Thank you!

**Oswin:** Thank you!

(Theme song – soft piano music)

**Anne:** We were speaking with Oswin Latimer, the founder of Foundations for Divergent Minds. They spoke to us from their home in Texas. If you're listening to this on iTunes or Stitcher, you can learn more about this episode and the podcast by visiting our podcast website at [NoncompliantPodcast.com](http://NoncompliantPodcast.com).

You've been listening to Noncompliant. I'm your host, Anne Borden King. Noncompliant was recorded at DB Audio and MCS Recording Studios. Various episodes were engineered by Dave Boir, Nathan Greavette, and TJ Liebgott. Thanks to our engineers and thanks for listening.

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allistic – not autistic

SLP – Speech-Language Pathologist

OTs – Occupational Therapists