



The Think Inclusive Podcast

Season 10, Episode 20

Hilda and Olivier Bernier | Forget Me Not Documentary

Audio Transcript

Tim Villegas

From MCIE. What happens when a family takes on the largest school district in the United States to advocate for Inclusive Education? You are about to find out.

My name is Tim Villegas from the Maryland Coalition for Inclusive Education, and you are listening to Think Inclusive, a show where with every conversation we try to build bridges between families, educators, and disability rights advocates to create a shared understanding of inclusive education and what inclusion looks like in the real world. You can learn more about who we are and what we do at MCIE.ORG.

For this episode, I speak with Hilda and Olivier Bernier. As 3-year-old Emilio prepares to start school, his family finds itself embroiled in a challenge all too common for children with disabilities-to secure the right to an inclusive education. Cornered in one of the most segregated education systems, New York City public schools, filmmaker Olivier and his wife Hilda turn the camera on themselves and their child with Down syndrome, as they navigate a byzantine system originally designed to silo children with disabilities. Hilda, Olivier, and I talk about the film *Forget Me Not*, which is currently streaming for free on Tubi. And give us an update about how Emilio is doing now.

Before we get into today's interview. I want to tell you about our sponsor, Together Letters. Are you losing touch with people in your life but you don't want to be on social media all the time? TogetherLetters is a tool that can help. It's a group email newsletter that asks its members for updates and combines them into a single newsletter for everyone. All you need is email. We are using Together Letters so Think Inclusive Patrons can keep in touch with each other. Groups of 10 or less are free and you can sign up at togetherletters.com.

Thank you so much for listening.

And now, my interview with Hilda and Olivier Bernier.

Hilda and Olivier Bernier, welcome to the think inclusive podcast.

Olivier Bernier

Thanks for having us.

Hilda Bernier

Hi, Tim.

Tim Villegas

So I saw Forget Me Not a few months ago, and it was so impactful. And I really wanted the listeners and readers of think inclusive to, to meet y'all. And to hear your story in your voice. And I don't know if you know this about me, but I was a former special education teacher, Hilda, I know that you are a special education teacher or former one out prepared were you to enter into this world in journey with Emilio, knowing what you knew, Were you prepared at all for what you were up against.

Hilda Bernier

So I I did feel prepared to some extent. But the challenges came up pretty, pretty abruptly. And pretty quickly. As educational professional, I wanted to give credit to all the people that were evaluating him, and that were walking us through the process and that transition from early intervention to preschool thought that people were working in good faith, and that, from my experience, as a teacher, I used to work in a school that was very welcoming of children with disabilities. And I taught mostly integrated classrooms at the time, what's what was known, then as ICT, integrated, collaborative teaching, from that experience, thinking that I could work with these people believing that I could trust their expertise. So you really caught me off guard to know that that he was going to be put in a trajectory that was not exactly inclusive from the very first day in preschool. So that was kind of like a bucket of ice water over my head. And I had to shake that off and have a real discussion with alleviate, to see what our priorities as a family were and how we were going to get to that. So yes, I was very familiar with the process as a professional, but when it came time to meet, for me to be on the other side of the table, it was a complete different experience,

Tim Villegas

just to be clear, am I not? I want to I want to be accurate. So were you a special education teacher, or were you a general education teacher,

Hilda Bernier

I have a license on special education with a bilingual extension. So I was catering to all those populations. And most of my most of the courses I taught were integrated, right, with the exception of a handful of self contained classrooms that I taught that where I was teaching high school at the time, I have to say that the self contained environment at that age, it's, it's so detrimental to the students, they hate it, they don't want to be there. It's very stigmatizing it leads to truancy, they, some of them just stopped showing up. And for some more targeted interventions, there was a lot of convincing students that that these targeted intervention serve like a resource type of intervention was necessary. So in those instances, it was a little better. But when we had, for the first time a cluster of children that has self contained IEP s, we really had to, we went through a lot of difficulties getting the students to trust us to, to buy into the

idea of going through high school. And it was very hard for them. Yeah, at which point, you know, at some point, we had to like have a discussion whether we wanted to, like dissolve those class, those self contained cohorts, because it was just not conducive conducive to any to anything good. Really.

Tim Villegas

Olivier, the film starts out with Emilio's birth. And so I was, as I was watching, what was your plan with that footage? And to begin with, because it surely wasn't to make this documentary?

Olivier Bernier

Absolutely not. No, I mean, you know, before being a father, I was a filmmaker. And it's just like a natural extension of my body to be holding a camera. And when Emilio was born, of course, I had a camera in my hand, the actual moment that you see in the film, though, the camera was around my neck, I didn't know I was recording anymore, because there was a lot going on. And the last thing on my mind was recording it. It was only after all the dust settled from that scene that I realized the camera had still been rolling, and took me about a year to just check if the footage was there, and then another year to actually watch it. So it was definitely not intended to be part of a documentary.

Tim Villegas

Yeah, and you could think of it a few different ways. It sets the scene beautifully. For for families, I was just at the club 21 conference in Pasadena where they showed it. And I overheard mom say, That's exactly how it was for me. Exactly.

Olivier Bernier

We I knew pretty early on that we had to include it in the film because we wanted to make the film as raw and authentic and as us as possible. And that was a really challenging moment for us because we were completely unprepared. But I think people need to see that. It's people need to share that experience in order to understand what goes on later in the film. I believe. At that moment, it was really felt like doom and gloom to us because I had never met anyone with Down syndrome, I had no idea what Down Syndrome really meant as far as living a full life. And that moment was really what set me on the path to making the film in the first place.

Tim Villegas

The scene that we're talking about is the moment when the doctors are explaining that there's something different about Emilio and, and I believe what I remember is the doctor actually saying those words down syndrome, is that right? Sure.

Olivier Bernier

Yeah, the from the moment they took Emilio to the incubator, I knew something was going on. All the doctors were huddled around him. And I looked at Emilio and could tell it see the slanted eyes and and my heart was pounding in my chest, what's going on? Why are they not talking to us? And then the doctor comes over and he says your son shows five markers of Down Syndrome and he goes through the five. And at that point, it's just you feel like you're out of

body. You just went through this experience. You're up for 50 hours or whatever it is, and then you're receiving and receiving this news and it see it's delivered to you almost the way it was delivered to us at least it felt almost Like your child is, is dying or something like that, like it was a very grave delivery of the news. And looking back on it, there's maybe a better way to do that, being that it's the first moments of your child's life, and you should probably be celebrating it no matter who your child is.

Tim Villegas

So in the film, it shows both of you going through a process of thinking about Emilio's education, and what your hopes and dreams for him are. And also, I picked up a sense of, I'm not sure inclusion is the right thing. Why was advocating for Inclusive Education, important to you, for Emilio, and maybe, was there a moment that you're like, this is the right thing to do?

Olivier Bernier

I can start from I think Guild and I both share different perspectives, because of the came from the professional world of special education. But we both agreed early on that we wanted our son included in society, we would do whatever it would take to, you know, that would bring him to swimming lessons, we would do as many activities as possible with him just to be around other children. And this is before school. And we knew early on that inclusion in life was a goal of ours. But I had just assumed that schools were all inclusive at this point, because we're in New York, it's a really progressive city, in those teaching and integrated classes, and I was just flat out completely ignorant. So when we started talking about it is that had reservations and probably go through some of those.

Hilda Bernier

Yeah, definitely. I did have my reservations, as I mentioned earlier, because I want to give credit to the people in doing that are trying to do their jobs, like people that are evaluating for physical therapy and occupational therapy, and speech and all these, I feel like the Tao in may stem from those reports. Because it really painted a picture of my son, that was not exactly the image I had of him, from experience from being here with him every single day, seeing him working with his therapist from early intervention on a daily basis. Like I know, like he was in my mind that he is going to get to where he wants to be or where he needs to be. Like, I'm reading these reports. And I started like, second guessing my own knowledge, because I read all the research when I was becoming a teacher. And we know that other research supports the fact that inclusion is beneficial for students with disabilities and students that don't have IEP s, the benefits are academic, and they are social. And there's no, there's no question that that is what we wanted at the moment. And that's what we are going to keep pursuing. Because there's no reason why he should be hidden away, he does have a very physical, visible disability. But at the end of the day, inclusion is just going to make everybody's experience learning experience, a better word.

Olivier Bernier

And the reports she is referring to are the evaluation reports, when they take your child, they look at them for an hour and determine what their future trajectory is going to be. But that's

what they use. And then you go into this meeting, I'm sure we'll get into the IEP meeting, but they try to sell you a bad car essentially, and tell you that your child's not good enough. And, you know, if they're coming from that professional world, there's part of you wants to believe what they're saying, even though you don't feel it in your gut. And then it was really, I think visiting the Henderson school that kind of change your perspective on an inclusion. Yeah,

Hilda Bernier

seeing when they do it at the Henderson school was phenomenal. We it was a life changing experience to me, because you really can see like the possibilities. You can you. I got to see it firsthand how you had children that had real challenges that have speech delays, to children on feeding tubes, you had neurotypical children that were just hanging out with everybody else like it was there every day. There was nothing strange to them. are different. It was, they were all learning with each other in playing together, though. And it was also very interesting to see that everybody in that building all the adults in the building, we're on the same page. Because to make something like that work, everybody has to be on board. And that is something that, that it will be great to implement in other places. The idea that that, that, as an educator, you can teach everybody has to become more prevalent. Because, yeah, there are Genet teachers, there are special ed teachers, but at the end of the day, you as a professional, you need to be prepared to cater to everybody. So you never know, like some kids who don't have IEP s and they still need differentiated instruction.

Tim Villegas

One thing that I've always wondered about Henderson and I've never been I've only seen Dan Habib's film there. And then of course, your, your film. From what I understand Henderson's part of Boston Public Schools, that right?

Olivier Bernier

Yeah, Henderson school is a public school anyone right into it. And there's a waiting list for neurotypical children. They tried to accept as many children with disabilities as possible.

Tim Villegas

So again, not like it's not necessarily a criticism. But I wonder why. Since Henderson is so successful, why there aren't more schools in Boston that have adopted that. So I don't know if you have any insight about that. I've kind of wondered that. A lot.

Olivier Bernier

Yeah. So one thing with the Henderson school is that it's part of their mission to spread this concept of inclusion and show how it works, because it's one thing to read about it and to talk about it. And to actually see it in action. Like when did this I just changed her perspective, and it became our mission to find a school like that in New York. There are a few completely inclusive public schools in Boston, more than New York, let's put it that way. And what's unique about Henderson school is that it's K through 12, or preschool through 12. Okay, that that makes it slightly unique, but it's also one of the first it was Bill Henderson who started the school. It wasn't called the Henderson school back then. But he started the school because he was losing

his vision. And he was a principal of a school and they wanted to push them out of his career. And he said, Wait a minute. That's not right. I'm going to start a public school for the deaf blind. And that's been the genesis of the school since the beginning. But yeah, there are other schools in Boston that are completely inclusive. Yeah,

Tim Villegas

I'm gonna have to get up there. I have not been to Boston, just out there.

Olivier Bernier

Yeah, it's something it's really something to see.

Tim Villegas

What was the immediate barrier for you coming in wanting an inclusive classroom in school for Emilio, what was the first thing that was that you ran up against? As far as getting him into school, or once he was in school, if I remember correctly, it started with the film shows an IEP to for services in pre K, correct.

Hilda Bernier

I feel like that meeting was the first obstacle that we had for to get him into an inclusive classroom. And it was very upsetting because when Amelia was evaluated, he was under three years, he was like, two and a half, probably. And at that meeting, they put the percent that so many roadblocks to prevent him from getting into that setting. That was really heartbreaking. Because I really believed that I was part of the team and that Olivia was part of the team that we could speak and from what we know about him, and what what our vision was for him and that somebody would actually listen by in the name of data in the name of data collection, they they had already decided that that he didn't belong in a general preschool setting. So for me, it was like whoa, wait a minute, what if these how it goes like these airily at three h three. And that's when I I was on the It's like a slap in the face. And I realized that we really needed to get an advocate in that we needed to draw our line in the sand and work for that.

Olivier Bernier

And then, at that time, we were really making a film about inclusive education. But we weren't really focused on Emilio's journey. He was part of the story, but it wasn't really the story. But we're making a much more cerebral film about what is inclusive education? How does it work? What is universal design for learning. And then as we're making this film, we see Emilio slowly getting pushed down this path of segregation, and two and a half years old. So we started filming all these things, and just muscling our way into these meetings with cameras, even though they really didn't want them. Because it was just shocking. From that meeting on it was just the whole thing. It was like, where am I living? How could they be telling it two and a half year old, that he doesn't belong in a classroom because he's never been in a classroom before? You know what, two and a half year olds have been in a classroom, right? So it was just from I felt like I was in bizarro world, and we just needed to capture it.

Hilda Bernier

The pitch was unbelievable. He's never been in a classroom, he's not speaking, he's not doing this, we feel a smaller environment will be better. And then he can move up. And just, it's unbelievable to think that a small child at that age has to work its way out of something, when he should have been just like, right off the bat just playing with the other kids and learning whatever they were learning and getting his services within that setting, which ultimately, it's what we were trying to push for.

Tim Villegas

Yes, yeah. Yeah. I think the whole film is powerful. The things that were really impactful to me were the IEP meetings, because that is that's the setting that I've been in, I've been in the role of an advocate and a representative of the district and advocating for the families. And it is, it's absolutely heartbreaking. And I felt that watching the IPS, because I you know, have been the district representative saying the words, right, about the data. In fact, that's so funny, you brought that up Hilda, in my training in the training that they, you know, the, my supervisor would give us on, you know, how to run an IEP meeting? And what if the parents disagree and stuff like that? I remember them coaching us that it always comes back to the data, because the data doesn't have a motion. That's what they said to me. Yeah. Yeah, that's what they that's the training that they give teachers, right? But how do you separate this kind of decision without any emotion,

Olivier Bernier

the entire trajectory of your child is being decided in that moment, New York, at least, it's very unlikely, almost impossible to remove a child, especially with a significant disability like Emilio's from a segregated setting. Once he's put into it, you know, you're really you're really feeling Wow. Glimpses of your son at 18 In that moment, and you're thinking about, who do I want him to be? And how can it not be emotional? But that's also why when people ask me, I'm always like, you have to get navigate, because it's almost too emotional. The moments too big. It's hard to be cool headed or to negotiator.

Tim Villegas

So I'm wondering, when you made the film, did you have a particular audience in mind to see the film? were you speaking to a specific viewer? I,

Olivier Bernier

as I was making the film, I really wanted to make the film for myself, before Amelia was born. So I was thinking about what would be understandable to me before my son was born. What was that bridge that would get me there to following this journey about IP, something I never thought about before Amelia was born. I wanted the film to be accessible to audiences that don't think about disabilities on a daily basis. The end of the day, I saw it as a story about our family being representative of what 1000s and millions of other kids across the world go through. So I really made it in a way that I tried to strip as much as the acronyms out of it as much. Some are still in there, but we try to explain them because it can be a little short. It was challenging for me going through it. And then the second thing is that we really wanted to make

the film a journey. We wanted to make it experiential. So I think that one thing I'm proud of what the film is that it, I watch it, and it still does feel exactly like it was going through it the first time. My heart still pounds when I see the IEP meetings, I thought that would have worn off by now, but it hasn't. No, I

Hilda Bernier

mean, I have that feeling every year when we have to review the IEP.

Tim Villegas

So why don't we talk about where you are now? Are you still in New York City? Or, like, what's the status there?

Olivier Bernier

So we have to cross the river during the pandemic, we're in New Jersey now. We, we went through a pretty long process of with the district, and we got pregnant again. And we had a second child. So I moved to New Jersey to house a little more room. But we also, you know, selected a district that we thought would be the most open to having Emilio included, not that it hasn't been a challenge where we are now but they've been a lot more supportive than they were in New York at the time, which has been great. Emilio, right now, as we speak, he's in kindergarten, fully included in general education class, and he's thriving,

Hilda Bernier

That he ameliorates getting so much out of this experience, he's just like flourishing in every way. And it's something that I see on a daily basis. So he makes me feel really proud of him. And because he's, he works so hard. And he also has turned into like a social butterfly. Um, and, you know, like, parents are like calling us to set up playdates and like, what else as a mother, and as parents we want, that's why we want inclusion, because, you know, he's having the experiences that any six year old, it's having, the school offers, karate at the end of the day, and yoga and hip hop, and he's doing it all. Like, it's, they are not telling me, No, he can't do it. They asked me, oh, he has a one to one para, will provide one for that part of the day. And you know, it's, it's, it's wonderful, in my opinion, knowing that the, the, that there are people that that will support your child. That way, it's, it's very beautiful. See, I feel very glad that we're having this experience as of now.

Olivier Bernier

And, and also, what's amazing is just the children, the same exterior experience we saw at the Henderson school where the children just don't see that disabilities. They see differences, Emilio's nonverbal, for the most part or low verbal, and they find different ways to interact. And it's incredible. The children are going to school with someone with Down syndrome, and they're going to take that with them for the rest of their lives.

Tim Villegas

There may be some families that are listening to this and are in a similar situation they're at a crossroads with do I continue to fight with my district to include my child? Or do I just say, It's

too hard? I'm going to accept the recommendation for them to go to a segregated and self contained classroom. It's not that bad, they get it, they got a good teacher, they can make friends. So imagine I'm that parent, what would you say? What would you say to them?

Hilda Bernier

I'd like to tell whoever is trying to make that type of decision. So it's a very intense emotional decision that they're embarking on. But I would like to tell them that, as a family, they need to first set their priorities. Parents need to do whatever they believe is best for their child and best for their family. Once those priorities are lined up, then you can find different ways to get to that. I know people that say, a gen ed class is not going to work for my child and I respect that. And to some extent, it's okay you know, that if it's not working out, then it's okay then then to seek for other options. But the family needs to do what the family needs to have some peace of mind because if there's no peace of mind and clarity, and priorities that are clear, then things can become very difficult and convoluted.

Olivier Bernier

And I come at it from a little bit of a different angle. Oh, when I think about a classroom and how I learned in the classroom, what my experience was, is that you learn so much about life in the classroom, you know, that is your first entrance into society, really. And really what you want to see in a classroom is something that mirrors this society that you want. What do you want for your child? Do you want your child to be included in the rest of life? Or do you want them to be segregated the rest of their life? So I think that's the absolute first thing parents should ask themselves, is what do you want for your child. And then the second thing is, was inclusion tried, it should just be the first option. There's some parents that have never tried it and have never fought for it. And the truth is that there's no way to know if it will or won't work. The second thing is there's inclusion done poorly, and there's inclusion done well, and when inclusion is done well. People work together to find ways to reach the child to make sure that he or she is successful in that setting. I think, at the end of the day, you know, you can talk about there's a law for inclusion, there's there's methods, there's all this, but it's what do you want for your child?

Tim Villegas

And for educators, too, because a lot of there's a lot of educate a lot of school leaders listen. So principals, assistant superintendents, team leads, what I guess specifically for the film, what do you want them to take away from watching the film?

Olivier Bernier

First off, I think educators have the most important job in our society. It's why I spent three years making a film about it, it's, I think, you're setting up your next generation with your public schools more than any other facet of society. And that job is really important and should be taken really seriously. So when in terms of decision, and they do a great job at it. But the problem is, is that we can't just keep doing things, the way they've been done before, just because they were done that way before. And I think that to improve our schools, for all people of all abilities, all races, we really need to look at what can we do differently to make sure that

everyone's successful. And when you think about inclusion is a really hot word right now. But when you think about inclusion, what does that really mean? And what that means to me is that every child has an opportunity to achieve their full potential. So how do we get there? How do we create a classroom? How do we create lessons that every child can achieve the best version of themselves? What about hopes and dreams for the film?

Tim Villegas

What are you hoping that the film? Well, I don't know how you want to say that. Oh, early, like that question. But we're just gonna keep it in there. You know? It's, yeah, standard question. I'm sure. Maybe what's next for y'all with? Forget me? I know, it's been a few film festivals. I don't know if it's still on to be.

Olivier Bernier

I believe it's the film still gonna be on to be? I think it's a fine question. We made the film for a reason. And really, the mission of the film is to spark conversation on inclusion. For people that are going through the same journey we went through, I think it's a tool for empowerment. For people that don't know about inclusion, it's an entrance into understanding what inclusive education is. So our hope really is to that people share the film, we had a great festival run, we won the slam dance Grand Jury Prize, we did really well, we were at the opening night film of the Human Rights Watch film festival. Those were audiences that were there for festivals. And now what we really hope is to kick off this grassroots kind of campaign with podcasts like yours, and to really spread the word of the film, because I think the more people see it, the more we can have a conversation, the more we can set a level playing field for what that conversation of inclusion is, in our core audience are people families that have someone with disabilities in the family. But if you could share that film with someone, I'll use my sister as an example who has two neurotypical children. She learned about inclusion for the first time by watching the film. And I think that there's so many advantages for all children in inclusive settings. So I hope that the film can kind of bridge that gap to families that don't have disabilities in their lives. And the other I was at a q&a the other night and someone asked, you know, why isn't there more inclusion everywhere? Is it like a financial issue? Is it a political issue? And I said was in New York, it's definitely not The financial issue because in 2021, alone, they spent a billion dollars on lawsuits, trying to fight inclusion and sending children to private schools. It's not money and then is it politics? Anybody could have a disability it doesn't matter what you believe in, and we're all affected by it. And it's all our duty to help people with disabilities. It makes us better people It makes us more empathetic and it gives us a different view into the world so I hope when you say what are your hopes and dreams for the film I they're just small those obsessive that's a little bit of

Tim Villegas

the world Hilda and Olivia a Bernie a. This has been a fantastic discussion. Thank you so much for being on the thing inclusive podcast.

Hilda Bernier

Thank you for having us.

Olivier Bernier

Thanks so much for having us.

Tim Villegas

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On the day this episode airs MCIE is hosting a webinar with Olivier Bernier and will play a clip from the film and have a Q&A session afterward. There is still time to register. We will put a link in the show notes as well as a link to sign up for our email list.

For more information about inclusive education or to learn how MCIE can partner with you and your school or district visit [MCIE.org](https://mcie.org).

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