

## Stories from the brainreels interview with Marilyn Lash

March 21, 2014

### Introduction

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CHERYL: Welcome to Stories from the brainreels. I'm your host, Cheryl Green, from StoryMinders up in sunny Portland, Oregon. This is a monthly podcast about brain injury and disability with a focus on art, culture, and disability pride. Contact me at [info@storyminders.com](mailto:info@storyminders.com) with questions or topics and guests you want to hear on an upcoming show.

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CHERYL: My guest today is founding member of Lash & Associates Marilyn Lash. Before I talk about her work and her company, here's a little bit of disability arts news.

On June 14, 2014, Community Empowerment Programs and Krip-Hop Nation are partnering together to present their first event in New York.

Here's how they describe the project on their Crowdrise.com fundraiser page:

"BUILDING UP OUR COMMUNITIES LOCALLY, NATIONALLY, AND INTERNATIONALLY THROUGH ADVOCACY AND ARTS, WITH WORDS, MUSIC, AND VISUALS. This event will build onto an annual community-based day of global interaction of artists with disabilities, community partners, parents, care takers, and allies. To display self-advocacy, artistic words, entertainment, and key note presentations that offer a variety of solutions for PWD's seeking to connect with integrated services and establish collective networks." If you're a regular listener of this podcast, you've heard me mention Krip-Hop Nation many times. Here's a chance to support their incredible work!

Go to [crowdrise.com](http://crowdrise.com) and search for "Community Empowerment Programs" or "Artistic Expression of People W/Disabilities & Their Allies" and donate today to support this amazing looking partnership and event!

### The Interview

On to today's interview: Lash & Associates Publishing/Training is a very unique company. They started in 1996 to fill a few important holes. #1: Too many families were being given medical texts and research journals that didn't really help them support their loved one with a brain injury. And 1996 was early enough that the internet wasn't filled with easy to find resources yet. #2, a lot of educators and rehab clinicians in community settings were having a hard time finding affordable and understandable therapy materials and research. And #3, there didn't seem to be much of anything about young people with brain injury. Enter Lash & Associates.

They started making tip cards and pamphlets that summarized the technical information. Their first catalog had 4 tip cards. Tip cards are small, written in quick, everyday language, and cover tons of ground. They now have over 100 different tip cards as well as booklets, DVDs, manuals and training kits. In 2005, they branched out to also address needs of adults with brain injury.

Now here's where the story gets super exciting for me. Lash & Associates publishes all these incredible materials for clinicians to learn about all aspects of brains, brain injury and rehabilitation. And their website ([www.lapublishing.com](http://www.lapublishing.com)) has somewhere on the order of 10 billion links to really specific information, just about anything you might want to look for. If I had actually become a speech therapist, I likely would have bought my books and manuals from this company. But I didn't go into the field. Yet, they still made a place for me and other peers with brain injury. They have a new, really gorgeous magazine called "Brain Injury Journey" that you can subscribe to and get a free electronic version online. You can also pay a small fee for a print version. It has lots of down to earth information from experts, peers and family members. They also have a huge catalog of things written for Spanish speakers and for young people of all ages. AND the blog. The blog is for experts, families, and peers with brain injury to publish posts. Anything. I've submitted posts about everything from how expertly I can ruin pancake mix to how hard it is to make a documentary film when you have trouble relating to people. Other peer bloggers write about how they got injured, what's hard to do now, and how they thrive. There is an incredible range of posts and posters. What's so exciting to me is how they include the peers and family members (like parents or spouses) as equals to the experts who are posting.

Too often, we are told we couldn't possibly know certain things because we're "only" patients with a brain injury or we're "only" a family member. I have to thank the folks at Lash & Associates wholeheartedly for giving us a space at the table. You can find memoirs and books on their site, and they even listed my first two comedy films about brain injury life.

Listen to a wonderful conversation with Marilyn on the Brain Injury Radio Network here on BlogTalkRadio. I highly encourage you to listen to what she has to say--and her very gentle, easy to follow, not-too-fast voice! Go to [blogtalkradio.com/braininjuryradio](http://blogtalkradio.com/braininjuryradio) and search for Marilyn Lash. She was the featured guest on a show with host Kim Justus on April 3, 2013. You'll hear her talk about how she got involved in work with brain injury survivors and families, how the company got started and why, and some amazing ideas and steps for peers who want to get their writing published.

So with that, I'd like to play my pre-recorded conversation with Marilyn Lash for you to enjoy.

### **Family history with brain injury and going into the TBI field**

CHERYL: So Marilyn, you've worked with people with disabilities and their families for over 35 years. And in the interview with Kim that you did in April last year, you gave a really moving story about your family's experience with your brother's Post-Concussion Syndrome after he'd had many mild TBIs. And then these experiences prompted you to go into Social Work. So my question is, was it difficult to work with other people with brain injury? Or do you feel like your family experience actually made it a natural fit?

MARILYN: Well, I actually slid into it a bit sideways or backwards. When I was going through watching my family pretty much disintegrate as my brother went through his decline and had to drop out of college and couldn't find a job. He went from being the All-star to practically being homeless at one point. So that was really what drove my interest into working with families and led me into Human Services. But in my early decision in terms of what field, I tried to stay as clear away from my brother's condition as possible. Because the piece that was missing was when my brother was hurt, it was about 50 years ago, which really dates me for your listeners. And I can remember my mom saying, there has to be some connection with all those concussions and all those football injuries. And everybody poo-pooed her because we really didn't know much about concussion.

We certainly didn't know much about Post-Concussion Syndrome 50 years ago. So when my brother went through that long slide with the cumulative effects from the concussions and then slid into quite severe mental illness, I made the decision that I didn't wanna work in Mental Health. Because that was the association that I had with my brother. So I elected to go into physical disabilities, not realizing until about 20 years later when people with brain injuries started showing up. And with now all the research on concussion, then realizing aha. My mom was right all those years ago. This was a brain injury. By that time, my brother died about 10 years ago. But I look back on that before and after of his life, when he was the star to a man who first had to drop out of college when he was 19, who lived until his mid-50s. But by that time had accumulated not only the multiple brain injuries but had also had severe mental illness, was on all kinds of psychotropic drugs, had a very serious seizure disorder, and also finally died after a stroke. And along the way, had also had electric shock treatments.

CHERYL: Oh!

MARILYN: So you put all of that together, and I think it's a wonder that he could function day to day, when I think about all the insults and the damage that occurred to his brain along the way. So it was a bit of an ironic twist that I wound up working in brain injury and now recognize that was my brother.

CHERYL: That's really impressive that your mother was picking up on that so early on. And I know that even though we've got so much information now, we still have things like when the NFL settled with all those players, they gave them some money but didn't admit to anything. They refused to admit that there might be a connection between multiple mild traumatic brain injuries and cognitive issues and mental health issues. Some of us are still really hesitant to make the connection. But you lived it first-hand, and you understand that it's real.

MARILYN: And the other little twist in this story with my parents is that they didn't live long enough to really learn about that accurate diagnosis. And on the one hand, my mother would have felt justified because she stuck to her beliefs all along the road even though a lot of professionals along the way tried to discredit her. On the other hand, it would've been a terrible blow to my dad because my dad was the football coach in the high school where he had the first three concussions. And so he would have really wrestled with enormous guilt by not recognizing it. And I can remember when I was a kid that my dad, during the football games, always had a pocketful of those little ammonia capsules. Now I realize we were talking about concussions. If anybody got stunned or dazed or what they used to call "getting your

bell rung," he would pop open those little ammonia capsules, and guys would shake their head and then back in the game they would go.

CHERYL: Wow.

MARILYN: So it's a whole bunch of different twists.

CHERYL: Right, right. But we only know what we know at any given time.

MARILYN: Right. And I can even remember my brother saying, "I'm not crazy. There's something the matter with my brain." So even with all his struggles, he knew that we weren't getting the story right and really did not know how to help him.

CHERYL: Mmhhh. But now you are, in a sense. Even though he's passed, you're doing the work now that would have been work that would have been really important to him.

MARILYN: Right.

CHERYL: To me, it's really beautiful that you are. I'm so glad you're doing the work that you're doing, with that history.

### **The decision to have a brain injury survivor as CEO**

CHERYL: So I'm extremely excited to see that Lash & Associates' CEO and one of your founding partners, Bob Cluett, is a brain injury survivor himself. And it's really not every day that organizations that serve people with disabilities actually have someone with that disability in a major leadership position. That's really exciting to hear. Can you talk about the company's decision to have a survivor as CEO?

MARILYN: Sure. And it's actually gonna sound like I really didn't make any conscious decisions about anything because this is another example of how I kind of back-ended into this situation. I first met Bob when I was working at a major medical center in downtown Boston. He did all my advertising and public relations for me. And then, down along the way, about 18 years ago, we got married. At that point, I was pretty fed up working in the research and academic community. And he had had a very successful career in the corporate community. And we both wanted out. So when we got married, we said ok, let's do what we want to do and not be tied to our jobs. And that was when we made the decision to start the publishing company.

So in that first year, as we were getting started, I remember one afternoon he said to me, "Well, if you and I are going to start this publishing company that specializes in brain injury, I guess I really ought to learn a little bit about brain injury. Can you give me something to read," [laughs]? I mean this really is a true story. I said, "Oh, sure, sure." And so I had this book I had written back when I was in my academic job called "Signs and Strategies For Educating Students with Brain Injury." So I gave him a copy of that. It was like a small book, probably about 80 pages, written in very user-friendly language. So he went off to read that with a cup of coffee. And he was unusually quiet for a couple hours. And then he came back to me, and he said, "This is my story." And I said, "What are you talking about?" He grew up in inner-city Boston in Dorchester, the working class town where "Good Will Hunting" was filmed. His family lived in

this three-story, what they call "triple-deckers" in that part of the city. So one of his favorite activities was to go out on the back porch--when he was a kid--to watch the planes landing and taking off at Logan airport. So he was doing that one day, and he had this sandwich that his mom had fixed for him that he didn't like. And so he figured he would throw it off the porch. So he climbed up on the bottom railing and leaned over so it would go under the porch when he threw it so she wouldn't see what he had done. And there's two key parts to this story. The first is that he was only four years old at the time, and kids are very top-heavy at that age. Their heads are bigger in proportion to their bodies than they are as an adult. So he was top-heavy. So the next thing that happened is he tumbled over the porch railing and fell off the porch. The second part of this that's key here is the porch was 3 1/2 stories up. And literally what saved his life was he hit the fence. And he still has the scar on his forehead. But he got up, walked back up three flights of stairs, walked into the kitchen where his mom was, with blood pouring all over him and said, "Mommy, I go boom."

Recently, we actually came across an old family scrapbook that he had, and we found the get well cards in that book that were sent to him when he was in the hospital. He was in the hospital for three days. But he had no visible signs of any kind of injury other than the cuts and bruises. He had no broken bones. But you need to remember that this happened--and again, Bob is now in his mid-60s--he went back to school. There was no Special Education at that time. There was no Rehab Act. There was no Section 504. He had a really hard time in school. What he said after he read this book was, "I always knew there was something different about me because I was different than my brothers, I was different than the other kids." And there were these inconsistencies in terms of his skills and his difficulties in school. But despite all of that, he went on to have a very successful corporate career building on his verbal strengths, his sales strengths, and ironically, put in place all the accommodations that he needed as he got promoted. He always had a great Administrative Assistant to keep him organized and to keep his schedule straight.

So when he was sitting there reading the manual, it was the first time that all the pieces of the puzzles fit together. And he realized, "I had a childhood brain injury." Now that he recognized it, he doesn't fight the accommodations that he needs. So for example, here in the office, we all see this kind of glassy-eyed look he gets around 1 in the afternoon. And he goes in his office, and he takes a nap for an hour. And then he's back, after that. But without that nap, things are gonna go downhill. So one of the strengths that he has brought to the company as someone who is a survivor is that he has this really innate ability to connect to other individuals who have had brain injury because he's also lived through the ups and the downs, the roller coaster. He's been fortunate in terms of being very successful, but it hasn't always been easy. And so he does bring a special perspective and a special gift to the company.

CHERYL: Once you identified it, though, there wasn't like oh well, I guess you can't be the CEO. His work history and what you knew about him spoke for him. And I think a lot of people run into they hear the term "brain injury," and they just get these associations: "Oh, it's gonna be a problem. They're gonna need too much, and they're gonna be aggressive and weird." And people don't take the time to find out what other qualities we have besides having survived a brain injury.

MARILYN: Mmhmm, you're right.

CHERYL: And so it's wonderful that you knew as much as you did, and he had that record, and you could look at it as one more piece of what makes him him rather than, "Uh-oh. He's gonna have some deficits that won't work for us." I think it's wonderful.

MARILYN: And in fact, we've carried that philosophy through with the company. We have hired some other employees who have histories of brain injuries who have really done quite well. And we thought, "Well, we should know how and be able to put whatever accommodations and supports in place that people need. This is our business, and if we can't do it in our business, then we're not doing something right." So that's always been a part of our philosophy. At the same time, anybody who we do hire who has any type of special needs or needs some accommodations still has to be qualified to do the job. That goes without saying. So it's been a good approach for us. And in fact, what we've found is that several of the people that we hired, they'd been through the experience of employers not being willing to even consider them, never mind hiring them. They've been through all those dead-end doors. And so they've been incredibly committed and dedicated to their jobs because it's been so hard to get that opportunity.

CHERYL: Yes, definitely. So that's sort of the company side of things.

### **Lash & Associates blog**

CHERYL: On the Lash & Associates website, you have this wonderful blog. I've written a few blog posts that you've been so kind to publish on the site. And through your blog I actually met another blogger, Amanda Nachman, who I was so excited to hear you and Kim talked about a lot on the other interview last year. Amanda got her book published with you, but I first found her when I read one of her blog posts and was really taken by it. Since then, Amanda and I have actually become friends, and we email quite a bit with each other. We've Skyped, and she's been a guest blogger on my blog a couple of times. It's really neat, and I wonder if you have any other stories of the blog actually connecting people or people feeling like they have a sense of community-building through the blog.

MARILYN: I do. The blog has really been a wonderful vehicle to build just that kind of community that you're talking about. And in fact, several of our bloggers who started out as guest bloggers have gone on to be incredibly popular and are regular columnists for our magazine. Janet Cromer, who started blogging with us about caregiving fatigue and compassion fatigue was incredibly popular. Rosemary Rawlins started out blogging with us on family issues. Nat Brown started writing about his experiences when he came back from Iraq. And so a number of the people who started out writing guest blogs with us really touched people out in the community and not only developed a real following but then have really expanded from there to become regular bloggers on Brainline, columnists for our magazine, many of them have their own blogs. And so it's really kind of like the octopus with all the tentacles going out. The blog really has a wonderful way of reaching people and allowing people to connect with each other.

I think one of the most touching things that we've seen happen with the blog over the last six months is Janet Cromer. Her husband, Alan, had a cardiac arrest and as a result had a very severe anoxic brain injury. Her blogs, we hear from more family members and individuals who are going through that nightmare of having a brother or a spouse or a parent have a cardiac arrest and survive but not knowing what survival means. Her blogs on resuscitating life after cardiac arrest have been the most popular

forum on our website. And it really speaks to how desperate families in those situations are, to not only find information but to find support. The blog really has a wonderful capacity to reach out and touch people, which I realized as I said that, I think is a tagline for one of the phone companies or somebody [laughs].

CHERYL: Oh! Reach out and touch someone. Yeah.

MARILYN: Right, right, right. But I'm gonna adopt it for my blog.

CHERYL: Absolutely, because it's actually doing that. And that's so wonderful because of course we need information. But there's only so much you can do with these statistics and, "Oh, in three months, you expect that and your scores and your 80% performance." That human to human connection, that person saying, "I'm going through it too. Here's what I tried." Or even saying, "I'm going through it too. I hear how hard it is for you."

MARILYN: Mmhmm, mmhmm.

CHERYL: That is really invaluable, and it's something that can't be given to you from reading a textbook or talking to your doctor, unless your doctor has personal experience as the caregiver or the survivor themselves. It's really unmatched to be able to say, "Yes, me too. I hear you."

MARILYN: Mmhmm.

CHERYL: I love that about your blog.

MARILYN: And what I say to people, cuz very often they contact me, and they inquire about, "Well, how do you go out writing for the blog? What do you decide to write about?" And I say, "Look at your own life. Look at what are the issues that you're wrestling with? What are the things that you're trying to sort through? Everybody has a personal story. But not everybody wants to hear the 9 million details about your story." Where people will connect is what are the issues that they're wrestling with? And it can be anything from dating to finding a job to finding a therapist. So I say to people, "Pick an issue and address that. Don't try to do your life story in a short article."

CHERYL: That's good. That's very helpful. You gave some good feedback to writers on Kim's show as well. And that's another really nice one. You know, the story feels so big, and you don't know what part to tell. But the beauty of the blogs is you can tell individual pieces and come back and tell another piece and another piece.

MARILYN: Exactly. It's like you wanna take the microscope approach, not the macro approach.

### **Keeping humor and peace in the workplace with dogs**

CHERYL: Now, on your website you have some staff photos, particularly I noticed your "Social and Security Team," which is composed of Buddy and Tucker. And those are dogs. I am so excited that you have dogs in your office. Anyone who knows me knows that I'm just shaking with joy like a little Chihuahua cuz I just am so obsessed with animals. But what I like about that is that Social Security and

getting benefits and applying for benefits, this is a really, really serious issue. It's hard. It can be humiliating. It feels dehumanizing. We often are denied. There's so much stigma. Social Security is not funny. But you've got these dogs, and you named them the "Social and Security Team." And you just bring this amazing sense of humor by giving them that name. And I just wonder, is humor a big part of how your company works, or is it just those dogs where that comes in?

MARILYN: I learned very, very early on in my career that. I started out as a Clinical Social Worker. And that's a tough job. People typically don't come to you with good news. They come because they're in crisis, their life is a mess, something terrible has happened. And so one of the ways that I have always coped, and I think a lot of clinicians cope, is you have to keep some kind of balance. And if we fail to see the humor in ourselves, then we fail to see it in the world around us. So it's one of the ways that we keep ourselves grounded. So, for example, Buddy--who's the chocolate lab--is lying right next to me, here in my office. And it's wonderful to have the dogs in the office cuz they're incredibly calming. Whenever we're stressed, we simply go over and visit the dogs. They have this little routine in the morning where they ride to work with me in the truck. And they come in, and the first thing they need is their water bowls filled up, or else they're drinking out of the toilet! And they get their morning bones. And then as the other people come into the office, they hit every single person up for a bone [laughs]. So they get a lot of snacks in the morning. And then, in the afternoon, they snooze away, stretched out on the carpet. And one of the things they're good at is not making sure that we work too late or too long. Come 5 o'clock, they know it's time to go home. And if we're not packing up, they will come sit by our desks and start barking and clearly tell us, "We've been good long enough. It's now time to go home. And then you need to feed me dinner." [both laugh.] So we love having the dogs here.

CHERYL: That's really sweet. You know, a lot of us--brain injury or not--have trouble getting a grounded, balanced life, and it does sometimes take someone else to sort of monitor that for you. And dogs are so great. They don't have any emotional baggage. They'll just come over: "It's five. Let's go."

MARILYN: That's right, that's right. And they're gonna love you no matter what. Doesn't matter how many times you screw up, they're gonna still come over and give you a big, wet kiss.

CHERYL: Yes! So now I really get the term "Social and Security Team." They sound extremely social.

MARILYN: Oh, they definitely are. And they do provide security. Nobody is coming into this building without them lettings us know.

CHERYL: Oh, that's great. I love it. And I just really--I mean, the Social Security application process is so awful, just to see that term used as a joke just really lightens my day and cracks me up so much.

MARILYN: They're both lab mixes, right from the rescue pound.

CHERYL: Even better.

### **Why do we always say we don't know much about brain injury?**

CHERYL: On a slightly different note, I hear people say a lot--all sorts of different kinds of people say-- "Well, we really don't understand brain injury because we just don't understand the brain that much."



And the brain is fascinatingly complex, but when it comes to brain injuries, I hear survivors, and I hear families telling basically the same story over and over and over. I don't mean an individual saying the same thing over and over, but across different people, they're saying the same things, having really similar experiences. And you can see it on the blog. You can hear it on the Brain Injury Radio Network shows seven nights a week. We have so much information and so many experiences, and we know so much--I feel like--about the brain injury experience, even if we don't understand exactly how a neurotransmitter essentially becomes a thought. But I wanna ask you as a publisher and a Social Worker and a family member of more than one person with brain injury, and just an all-around compassionate person that you are, I wanna know what your opinion is, just on the opinion level. Why do you think that the medical community keeps telling the public that we just don't know very much yet? Cuz I feel like, in terms of what we need to do to get by day to day and even in the long term, we know a ton.

MARILYN: Right, right. I think it's a couple things. I think in the medical community, people tend to look from the perspective of the science and the structural and the chemical changes in the brain. And that is clearly still a field that is still evolving. And it's slowly making progress as the different imaging techniques and medications and treatment guidelines are progressing. But I think that for the rest of us--the families and the survivors and the people in the community--we're looking at it more from a holistic viewpoint in terms of how that injured brain is affecting our social life, our functional abilities, our cognitive skills, looking at that bigger picture.

A lot of the misconceptions come because so many people with brain injuries look good. I hear the same stories over and over and over again. And a lot of it comes down to if people can't see the disability, if they can't see the physical damage, it's so hard for them to understand what's going on in that brain and how it affects just about everything else that goes on. So I think that's a battle that is still being fought.

I think one of the other reasons is that the brain injury community has always had a bit of a struggle in terms of having role models or leaders in the field. You look at what Christopher Reeve did for spinal cord injury through his terrible accident. That was very, very visible. No matter what you personally thought about Jerry Lewis's fundraisers for Muscular Dystrophy, he got a lot of attention focused on that diagnosis. The brain injury community has struggled in terms of what is our identity? Bob Woodward (ed note: Bob Woodruff), to his credit, really stepped forward when he was injured in Iraq and allowed himself to be very visible and very vocal. But I still don't see that leader in terms of the person who looks "normal" that is leading the initiative to help people understand that looking good isn't necessarily the same as functioning good. And so there's an awful lot that still needs to be done.

And again, you even see that in the media today with the returning soldiers. Even though you constantly hear the tagline about brain injury being one of the signature wounds of the conflicts in Iraq and Afghanistan, when you look at the images that are portrayed, you see many more images featuring veterans with amputations. Again, the physical injuries. Even in the military world, the vast majority of the war-related injuries are in that mild category where it's not as visible. So we really need to do an awful lot more in terms of public awareness and what is our image of who we are? And who we are is everybody! It's everybody from the person who looks fine to the person who has very significant visible disabilities. It's the full range. And I think that's the message that we're not portraying effectively.

## Mild TBI versus concussion and identifying injury in children

CHERYL: Mm. I think brain injury identity, that is a term--I think you might only be the second or third person besides myself who I've ever heard actually put those words together: "brain injury identity." It's just not even talked about. I read an article from a military study about mild brain injury. And this study concluded that Post-Concussion Syndrome is psychological in origin, and so to encourage service members to not over-identify with disability, they encourage people to not use the term "mild traumatic brain injury" because then you get a brain injury identity when all you have is a psychological problem after getting your bell rung. So they encourage the use of the label "concussion" so that that identity is not formed or can be kept at bay, which I found so interesting because most of the work that I do is all about identity. So anyway.

MARILYN: Actually, we've had the same experience with that. Identifying brain injuries in children is another whole arena. One of the things we know is that there are a lot of unidentified and misdiagnosed children with brain injuries because children with brain injuries tend to have quicker physical recoveries than adults do. And also because their brains are still developing, the damage typically doesn't show up until those portions of their brains continue to develop. And so it shows up in school as work gets more complicated and so forth. But one of the things we know is there's this real stigma about the word "brain injury." So that if you screen students in schools and talk with their parents, it depends on the questions that you ask. If you ask, "Has your child ever had a brain injury?" probably 99% of those parents are gonna say no. You will get a different answer if you ask, "Has your child ever had a concussion? Has your child ever fallen from a height of over 8 feet? Has your child ever been in a car crash?" You start to get very, very different answers cuz "brain injury" is the word that parents do not wanna hear.

CHERYL: Oh, yeah.

MARILYN: Somehow "concussion" seems to be less serious, less significant, kind of more acceptable. But it's still, again, helping people understand that a concussion is a mild brain injury. But very much the words that you use when you query people depends on the response that you get.

CHERYL: That is interesting. I mean, the thing with mild TBIs, I've had many, MANY that were so mild you don't even have to count them. They can be extremely mild. And I think people, like you said, they're scared of the term "brain injury." But it really can be something that goes away in the few seconds. Now, you do it too many times, they're adding up. And that's a problem. But I've had some that were very significant mild TBIs and some that were very mild mild TBIs.

MARILYN: Mmhm. It's the club that nobody wants to join.

CHERYL: That's right. But if you join it, you can't go back in time and unjoin it. You can only imagine when your precious, very young child might have gone there, you don't wanna talk about it.

MARILYN: Right.

CHERYL: Nope.

MARILYN: And the other disconnect that happens--and I'm generalizing a bit here, but---people in the medical field generally don't give parents the advice in terms of monitoring their child's development for any long-term changes from an earlier injury. And part of that also is parents wanna believe that their child is fine. That don't wanna see the warning signs. But until we educate families, particularly with children, about the developmental impact, it can really make a difference, particularly in school for getting those supports that the kids need.

CHERYL: Right. That's the key is when we can say, "Ok, this really was real. This really did happen, well now what do we do?" Cuz that denial feels really good, but then you don't take any action. And so the wonderful part about accepting it is that then you can start finding the resources and finding the ways to modify your communication, the way your family works, the way things work so that you're the most supportive and that you get the most support.

### **Brain Injury Journey magazine**

CHERYL: I mean, I think parents probably don't get nearly enough support for what they're going through in this amazing amount of uncertainty. So I like that in the magazine that you put out, the "[Brain Injury Journey](#)," there is always stuff for the families and parents and caregivers. There's always support in there. And it can never be repeated too many times.

MARILYN: Yeah, I agree. I really love the magazine. I think of all the things that we've produced, the magazine is just my favorite project. We have the most wonderful team of writers. We made a decision early on that we wanted the message to be "hope, help, healing." So we've crafted the magazine really carefully so that we always have columns that appeal and that are written for families, for caregivers, for survivors, for veterans, for educators. Yeah, we're tremendously proud of the magazine.

CHERYL: Yeah, yeah, you should be proud. I know your company takes pride in having things written in user-friendly and reader-friendly language.

MARILYN: Well, I give a lot of the credit to the magazine's editor, Barbara Stahura. She and I have worked together for a long time. She works directly with the authors. And a number of the authors for the magazine not only have personal experience with brain injury as a caregiver or as a survivor, but they're also professional writers. So the quality of the writing and the information is just terrific.

CHERYL: It really is. The quality, the variety, but there's still a unified message. It's very beautiful looking. And I should also let people know that you can get it online completely for free. People can pay for a printed subscription, but it's available online on lots of different people's websites. We have it available on the BIRRDsong website ([www.BIRRDsong.org](http://www.BIRRDsong.org)). People can go straight to your website and get it ([www.lapublishing.com](http://www.lapublishing.com)). Your company publishes and sells a lot of really high quality materials for clinicians to use when they do rehab with my population. And I just wanna say as a side note, I remember when I was a speech therapy graduate student, I went to your site, and I got all excited. And I thought ooh, this is where I'm gonna get my books after I graduate. This looks like a great company. I didn't really look beyond the books for clinicians. That was sort of where I was coming from was I'm gonna be a clinician, and I'm gonna get my books here. In the rehab world there are lot of clinicians--and there are getting to be more clinicians--who really want to get the client's perspective and center the

client in their rehab goals and their therapy. And then there are clinicians who, for whatever reasons-- and sometimes it's fear and a lack of confidence, but--some don't wanna stray away from anything that's not published in the journals. This is the technique used in the controlled clinical trials, and this is what I got from my manuals. And they don't wanna deviate from that. And there are researchers and clinicians who say that the client's perspective and the client's stories are "just anecdotal." And I have heard that before from clinicians, not in the brain injury world but in other areas. And the idea is that maybe anecdotal information will just tarnish the research, or it will tarnish the rehab. You can't go with anecdotal stuff cuz that's not what was in the journal. So your company's work is about providing information for hope, help and healing. That's the tagline for the magazine, but it goes beyond just the magazine. Boy, can you follow anything I'm saying [laughs]?

MARILYN: No, no, I do. I do. I feel exactly as you do.

### **Starting Lash & Associates to support families and survivors**

It's really one of the reasons that we founded the company because I felt like too many clinicians and researchers discounted the personal experience of families and survivors and caregivers. And one of the things that really bothered me when I was working in that arena was when I looked at the literature on families, for example, they were really largely portrayed as pretty dysfunctional and were looked at from a pathological perspective. I found very little in terms of how we could help families and where are families' strengths. And so I was always very, very frustrated when I was in those clinical and research settings in terms of well, how do we recognize and address the needs of families and survivors? We don't have the luxury of waiting for the research to catch up with Mrs. Jones, who is sitting in my office going through my box of Kleenex, who needs some support and advice and needs some direction.

CHERYL: Yeah.

MARILYN: So one of the things that I always did in those early days and really helped develop our product line for the company was some of our products are developed specifically from research, evidence-based practices and written for that clinical audience. Other products were largely developed from focus groups consisting of families and survivors and direct caregivers. And so my back goes right up when I hear people dismiss survivors' and families' experience as "simply anecdotal" because I think their experiences are absolutely critical. And we have the opportunity to learn a lot for them if we will simply listen and ask questions and put our own biases and agendas aside. Then we can learn an awful lot for them. I see that in our product line. We have a line of workbooks. For example, Barbara Webster's workbook, "Lost and Found: A Survivor's Guide for Reconstructing Life After a Brain Injury." It's one of our most popular workbooks because the content was largely derived from the support groups that she ran over many, many, many years with the Brain Injury Association of Massachusetts. She took all those words of wisdom, strategies and organized this into a workbook that is organized along executive skills but done in a pragmatic way so that Harry, who is trying to figure out how to organize his apartment will be provided with the tools to do that. With Mary, who gets lost in the grocery store, she provides some strategies.

So I think that unfortunately there still is like a great divide between the clinical and research world and the survivor and the families and the community world. And we need to start to bridge those and to recognize that each of those communities has expertise that needs to be shared with each other and that we can learn from each other. Because otherwise, we put families and survivors in the back of the bus. And that's simply not right.

CHERYL: I've done conference presentations, and I do guest lectures for the graduate speech therapy at a couple universities. One thing that I say is, "We don't actually come into your clinic room because we want to get better at divided attention and alternating attention. We want our lives to be better."

MARILYN: Right.

CHERYL: "That's our ultimate goal. And whatever things we need to work on, the reason we're working on it is because we want improvement in our lives, in our relationships and all these things. So we don't always have a lot of motivation to just do these little worksheets and handouts. And it's not because we're not compliant. It's because we don't always see, or we don't care about, these little tiny things, cuz we wanna work on our life as a whole." And I want clinicians to feel confident that there are ways-- and like you said, it's by listening to the survivor, to the client and the family and they wanna work on. There are ways to do these measurable goals and bill insurance and take data and do those things you need to do but with your eye on this person improving their life rather than your eye on these discrete cognitive functions. You know, I got pretty good at filling out worksheets when I was in rehab, and it made no difference in my life. Because actually, in my life I don't fill out worksheets.

MARILYN: Right, right.

CHERYL: So the worksheets have a wonderful place, and they're research-based worksheets. And they're important, but they're not for everyone, and they're not to be just thrown out and, "Ok, good. I can bill this person for the work." I've never practiced as a speech therapist. I don't know what the pressures are like. I don't know how hard it is to balance a full caseload and write your chart notes and bill insurance and go to your meetings and supervise: all this stuff. I know that it's got to be so rough. But if you listen to what the client wants, we do a lot of the work for you. We'll tell you what we wanna work on, and then we'll work on it with you, and we'll make your job easier again.

MARILYN: And I've always said that one home visit is worth 100 office sessions, that the more we get out with people in their lives and in their homes, then I think the greater the impact can be. Because then you see what the person's world is like. And the person's world is very different than it is in your office.

CHERYL: That's right!

MARILYN: So again, it's bridging that divide between clinical worlds and the real life-world that's really the key. I had an experience early on where I was doing some home visits with families, and I can't tell you how many families I met who said, "This is what the therapist gave me." And it's a copy of an article from the "Journal of Head Trauma Rehab". It's a great clinical journal. It does not make sense to give a

family a research journal that is 80% about research methodology. It had no relevance for what they were dealing with day to day. And so that was really how we came up with that line of tip cards that we have, these little 8-panel pamphlets. Cuz what families said is, "Stop giving me these articles that I can't understand. I need something I can read in 5 to 10 minutes. I need something in language I can understand. I need to be able to put it in my pocket or my pocketbook so when I go see my therapist or my counselor or my doctor, I can take it out. And I can review it with him. And I need to be able to take in this information when I'm sitting having a 15 minute coffee break cuz the kids are out at play" or whatever. So that was how we came up with that initial line of tip cards. It was a direct reflection of what we were hearing from families of how they wanted to receive information.

## Wrap up

CHERYL: Is there any other information like contact information or anything that you would like to share?

MARILYN: Yes, if you could just let people know we'd love to have them visit our website at [www.lapublishing.com](http://www.lapublishing.com). You can also access the blog on the website, and the magazine is there. All the products are set up so that you can preview any of them. You can look at the table of contents, read an excerpt, learn about the author. And we really mean what we say on the website, which is, if you've got any questions, just call us. And we'd be glad to help you. And I should give the number: 919-556-0300.

CHERYL: I really appreciate your time to talk to me and share about the work that you do and share stuff about your personal experiences too. That's really meaningful, especially for building bridges across the communities of people with brain injury and people without. I would like us to have more bridges going in both directions. And I feel like your company does that, and I feel like you do that really wonderfully well. So, thank you very much for coming to be on my show today.

MARILYN: Well, thank you so much. This has really been delightful.

[music]

CHERYL: Thanks for joining me for another episode of Stories from the brainreels. Find more handy info on brain injury and disability art and culture on my disability arts blog, [WhoAmItoStopIt.com](http://WhoAmItoStopIt.com).

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