Transcription

[Music]

[Lawrence] Welcome to TalkLD this morning. It's my pleasure to have in the studio Lynn Ziraldo. How best to describe Lynn is tough because if I think of the rights of those with Learning Disabilities in our province and if there was ever a definition of someone who advocated for them, Lynn's photo would be right there. Lynn has recently graduated, I know that she doesn't like the other word, the "R" word as we call it, we'll get to that in a minute, from the LDA York Region's Executive Director to a kind of special consultant role. Basically, what you need to know as a listener of this podcast, is Lynn has been advocating in this field for 38 plus years. And frankly hasn't stopped. So that number is going to continue to climb. All she is doing is changing avenues and venues, I believe. So Lynn, welcome to TalkLD this morning. It's great to have you as our guest.

[Lynn] Thank you.

[Lawrence] So, the topic today Lynn is to talk…I think actually I'm going to start with a historical perspective. We're going to talk today about how you become your child's advocate to give parents a kind of, a bit of a roadmap to help them, guide them through the process. But I want to start, given the amazing amount of history you have in the field, let's just ask this question first, if you think of the road that you started on 38 years ago, which I know you began advocating for your own son, which we'll talk more about in due course, compared to the landscape you see today in Ontario, 38 years later, what should parents know about how it has changed in that time? Has it got better, Lynn, over the 38 years?

[Lynn] Well it definitely has gotten better over the 38 years. I mean when I started my journey 41 years ago, the Education Act hadn't been revised to deal with Special Education, and that includes learning disabilities. I think what I would say, probably the biggest change is that we now know the value that parents have in that meaningful engagement is really crucial, and we also have put so many pieces of legislation in place to ensure that the systemic barriers that were there back in the early 80s and 70s are no longer there, but it's the implementation of that and the people you deal with. And I think the one lesson I've learned over the 41 years is about relationships.

[Lawrence] Okay. So, let's talk about the start of your journey as background to this topic today. How did you end up in this field in the first place?

[Lynn] I started in the field when my son Wade was born 41 years ago and he started off with a variety of medical complex needs. So we learned very quickly that we had to advocate on his behalf, and then as we progressed, we started to see some of the academic needs that he would need because it was in the severe language area in the learning disabilities. And so as we were starting our journey, and

remember this was 41 years ago, so in the late 70s we did not have the services that we needed for early identification. We didn't have as many speech and language pathologists that we needed for kids with language. Getting the diagnosis of learning disabilities and we started with Sick Children's and moved to now, which is called Hugh MacMillan Centre, etc. So those area for Wade, I learned very quickly, that I know him better than anyone. I'm his mom. I know him. If I'm realistic and reasonable then, you know, please listen to what I'm saying. I'm not gonna tell you how to do your job, but this is what I believe we need. And so it was a journey for everybody to learn that I wasn't backing off. If my question didn't get answered the first time, I would ask it again. It's not what you say, it's how you say it. So for Wade, we know we had to look at what the policies were, what the legislation was. Yes he has to go to school at age six, but did he have to start at age five? Now, of course, it's at age four. You know. But we have a lot more services in place and supports in place in our schools. And I'm lucky my sons were educated in York Region and I'm proud of that. You know, they worked with us and they had to work and I wasn't backing off. I'm still not backing off.

[Lawrence] Right.

[Lynn] So as we moved through. And Wade had to be in a small setting, because of the severeness of his thing. That's the tier three, or what we call tier three today, for that 51% of his day and then integrated where appropriate, for feeling like he belonged. So we moved through that whole education. The transition components is still a challenge today, of dealing with transitions. For families, you know, it's like you're constantly asked when did they first talk, when did they first do…and you think they're testing the parents, but really the system wants to understand the whole child.

[Lawrence] Right.

[Lynn] And I think that's the piece for me is I felt very strongly as a mom, that I wasn't gonna cut Wade up in parts, and that you really needed to look at him as the whole person. So his physical needs, his academic needs, his intellectual needs, his cultural needs, his social needs and his emotional needs. And so I would say that when you look at, do we still have stigma attached today to learning disabilities? Absolutely. And that's partly because we still have a society that wants to call it everything else than what it is. You know we wouldn't do that in the health system anymore.

[Lawrence] Right.

[Lynn] If you have cancer, you say it is cancer. If you have a learning disability, it's a learning disability. So there's still a stigma. I think the accommodation piece, the technology piece has increased considerably to now to what it was before. I think the area of everyone working in a team is there and that includes the parents, especially when we're looking at some of the implementations of the individual education plans. But parents have to believe in themselves. So they have to develop some of those skills to know or have people that can assist them on how to advocate for their child.

[Lawrence] And that's the perfect, that's where I was going to go with my next question. So, as you know, I've got two LD boys in my life. So I've been down this road a little bit on my own. How can we advise a parent, and let;s talk early days of diagnosis, which you and I both know generally by the time you're getting an assessment, you're probably into grade three or four, is the reality, you've probably noticed some issues. Hopefully, the school's jumped and done some things. Maybe, you know, an IEP written in some cases before a formal assessment. But I think as parents, when you first talk about approaching your son's or daughter's teachers, approaching the principal, how do you start that journey of equipping yourself, because that to me was one of the scariest things. I had very little knowledge. I, like you with Wade, knew Jake was not getting on at school the way he should. I saw some of the obvious signs. How do I equip myself though, because let's be honest, I think we always have that inbred from when we were kids, fear of going to see the principal.

[Lynn] Oh yeah. Absolutely.

[Lawrence] So how does a parent start to build their knowledge, Lynn, to be able to have an intelligent conversation with the school?

[Lynn] I think, from my experience, I got involved with the organisation. You know, I said, "okay, I cannot be the only parent out there" and so, now with with Google and Yahoo and everything else, you push a button and you get all kinds of information and you got to really understand what that means. And so, I always say to parents, the first thing you really need to do is have a basic understanding of what learning disabilities is.

[Lawrence] Right.

[Lynn] And so, either you can get that from the psychologist, you can get that from a teacher who is helping you or you can come to this organisation on learning disabilities throughout the province. And just have a better understanding of what learning disabilities are. You know, using our websites, it's accurate, it's got the information and that's what you need to start with because you can be bombarded. And I remember getting so much information and saying, "hm, that doesn't sit well with me, I'll file that and see where I'll start later." So try to gradually develop your own little profile of your son or daughter, and looking then at, "okay, is there any legislation that I need to be aware of?" You don't need to understand the whole Education Act, but you need to understand that you do have some rights.

[Lawrence] Right.

[Lynn] And that parental rights today, in our Regulation 181, for example, is so important. That if you have a concern, there is a process and every school board, and I always recommend go now to the

school boards, every school board now has a brochure, it has a parent guide explaining the different processes. But you can read it and think, “oh I understand it”, but there’s still jargon. You know, even though you try to make it parent friendly and that when you need to sit down with another parent, even another parent or someone from the organisation, to say “can you just explain this to me” and the bottom line is, if you don’t understand it, then go back to the principal of that school and say you know I got this brochure but it’s not making sense.

[Lawrence] What does it mean?

[Lynn] What does it mean?

[Lawrence] What does it mean to my child?

[Lynn] What does it mean for me? So if I ask that I want to have a meeting, can you refuse? No you can’t. You know…and so, I think for me, it was starting to understand the different pieces of the legislation. And I had a favourite phrase back then that I would always use, I would say, “is it in the legislation somewhere? Could you direct that to me?” There’s a lot of things that weren’t in legislation, but it was people’s perception that this should happen.

[Lawrence] And certainly with the provincial hat that I wear, of course, we understand that school board to school board the way certain policies are implemented, is completely different. And parents are shocked when I say, “which school board are you in and now let’s look at what they generally do.” And it’s not that there’s a right or wrong there, it’s just that they are different. Let’s also talk Lynn about, because I think one of the things you do very well, and I’ve noticed it, that you’re great at, sha’ll we say, deescalating anything that would be seen as conflict language. One of the things that I think I’ve learned from you is, let’s have the dialogue, but we’re not actually competing in that dialogue. We’re trying to get understanding, is that fair of the start that you started developing over the years?

[Lynn] Absolutely, being angry wasn’t going to help me. It wasn’t going to help the situation. Being in denial wasn’t gonna help the situation. So that whole grieving process. And I had some great mentors. You know, people who said, “what is the business we’re in?” The business we’re in is students, children. And I keep that in the background of my mind all the time. Is that, is this what’s best for kids? You know and you know, when I was working with Wade, it was, is this in his best interest? And if my stomach said it wasn’t then we needed to continue talking. And I would say, you know, we’re going to agree to disagree. And that’s okay, but what are we going to do to move forward? Because we can’t go backwards. We need to move forwards. So one of the documents we created back in 1997, *Shared Solutions*, is an excellent resource on the Ministry of Education website, and that’s the other piece that’s really helpful now, is that so many of these pieces that you need to know are on the Ministry of Education website. They’re on the learning disabilities’ website. They weren’t anywhere before, you had to go searching…

[Lawrence] Go searching a public library microfiche.

[Lynn] …a public library or when you got on the internet it was so many things. And so, for me it was, this isn't working being angry. If I'm going to really make a difference for my son and then gradually help with other kids, then I needed to develop those relationships. And learn the value of where they're coming from and the value of where I'm coming from. You know, and that was tough sometimes and you know sometimes I would set a goal. I would say to the parents, "set a goal. What do you want to accomplish this year?" If your son is five or six, let's not worry about secondary and the world of work. Let's just be, I was always two and half years ahead of where Wade should be. That was my goal because Wade was very complex. So being two and half years, I would look forward and say, "okay, well this is not good, there's no program for him, at secondary what are we gonna do about it?"

[Lawrence] And I think Lynn, it's very important, I just did a podcast yesterday actually for educators on some of a similar topic, and I think one of the things that I noticed with educators at times is that, and not all teachers by any sense of the imagination, is those parent communications, they can be a little defensive. Equally what I think we're saying here as a parent podcast, be careful what comes across as aggression to a teacher, because your kid comes home, they're in a mess. I always say, and I said it yesterday, and I'll say it in this podcast as well, my biggest regret and biggest mistake as a parent was the homework battles I had with my boy where I wasn't taking into account his capabilities and skills. I was looking at a workload he wasn't achieving and I was getting very frustrated in that. And to this day now, and you know I tell all parents, listen, know your kid, set realistic goals, but remember what you're seeing in the home you need to communicate, but you've got to try and control your emotions before you communicate it. Because otherwise it becomes toxic.

[Lynn] Well, and emotions cloud judgment. You know when I do workshops with parents and teachers, I give them the same message. You know emotion clouds judgement. So if your emotion is interfering with what you're trying to do, you need to stop, rethink, chill. You know, and work from there. I think the other thing we need to remember is that when I started my journey everything was being done for families. I had no input. You know, you had no input; your information was not shared with families. Unless you really pushed, you didn't get it. But then when you look at the nineties, and after Bill 82 in 1980 and on to 85, then it started doing it for families. So that was okay because families had some input, some transparency, they were here to help you. You know it was a phrase people were using a lot. And then, you get into the 21st century and it was, we need to do it with them. You know, people say parents can move mountains. We've seen this. You know, for professionals they have rules that they have to follow, they have so many other children, our little one is the only one we're concerned about. And then there's the rest. And so now they know that families have a source of control, they have a source of shared knowledge in decision making. I think that they want to walk the talk together. But for some, I always used to sessions on skills to be between passive, aggressive, and assertive. You know being passive about having a child with a disability is not really where you want to go, you need to learn

to get beyond being passive. You don't want other people making decisions for you. You want to be part of that decision-making. Being aggressive, using…pointing at them, yelling at them, you know, I would just stop and say you know what this isn't gonna work. We need to talk more. We always need to listen and sometimes we just need to listen to get their anger out. Being assertive is okay. I understand everyone's point of view, but in my opinion, for my son, this is what I believe. And they may not like it, but they'll respect you. And you know that is the key, is that you never know when you're gonna meet that next teacher is the principal of your kids next school, or that principal will be the next superintendent responsible for special ed., or the next minister of education who's making decisions on education policy. And I learned very quickly when you're an advocate, is we have rights [inaudible], we also have to know our facts and we have to research that. But for parents, just remember who is your child and involve them. I'm a great believer way back when, to involve my child in every decision-making.

[Lawrence] Right, because ultimately we do know that continuum of, as they get older and go to high school, to some extent you want to hand them the batten for advocacy to them for when they get to the correct age for it.

[Lynn] Absolutely, and I always used to remind parents that when they were angry. You're the role model for your child. So if you're angry…

[Lawrence] That's very interesting.

[Lynn] …what do you think is gonna happen? We're talking about children who are smart, who pick up things we would never think they're picking up. You know, despite of their disability, they have a lot of abilities and lots of insight, we need to remember. So never criticize, his teachers in front of him, his medical people in front of him. I would always say, you know what, we're working it through. You know what we have, and you need to be involved. He was part of the communication because that was helping his language deficits.

[Lawrence] And it's also going back to your kind as an individual because one of my greatest frustrations was as parent was the piece of software at the time, which will remain nameless, that they were throwing at every kid with an LD because they thought it was the answer and it didn't work for my boy. And I had to go to a number of meetings and kept saying to the school, this is not helping. And literally at the end of the day I took the action route, we went out and got some really good keyboarding skills, for a period of about six months. He never used the software anymore, but with a computer, he overcame all of his issues, his dysgraphia of not being able to get his ideas down on paper. But the school was so fixated on this solution will work, because it had worked for other students, and that's great, but that's not my son. My son has a unique profile, and this is not helping them. I'm telling you in the home environment, this is not getting us any further forward. They looked at me at times like I had

two heads because they felt, and to be fair the field continues to evolve, but at the time that was our solution, it must work for him. Well no it doesn't.

[Lynn] And that's where I would say is it written down that you have to have that program or that specific strategy, and it most cases it wasn't. We have the same area to do with transitions, you know like, well he's graduating from grade eight to grade nine, well I said well he's not ready. So you know, I think you know, well we've never done that. Well I said well there's nothing that says you can't. So instead of starting in September in grade nine, he started in second semester, in February. And that was, he was ready then. He was ready then. And if he got some credits, all the power to us. You know because I knew the legislation that he has the right to be in education five, six, seven years if he needed to. You know even if we're pushing for four, back then it was five. He has a right to be there longer if needed and it was the best strategy. But they weren't sure. He never went to his local high school, you know because of his medical health reasons he couldn't go there because the school was under major renovations. So you had to work it through, you know I would say pick your battles.

[Lawrence] Yes.

[Lynn] Pick your battles. Choose what you want to be that priority for that year and sometimes, you know the self-esteem of the kid is more important than making sure that that homework was done.

[Lawrence] So lets just follow this a little bit because I think there's an interesting tac here, Lynn. As you know we do a lot of work with the demonstration schools. I did a podcast with student there not that long ago, who when he went to the demonstration school, I think he was in grade nine, was reading at grade two or three level. And we know those are the absolute worst cases. Kids who really need extra and significant extra help. But one of the things that I think continues to be a battle for parents is this inclusion model. Because it seems to me you actually now talking with Wade about keeping him down a little while, right, because his maturity skills, whichever your reasons were.

[Lynn] He was a December baby.

[Lawrence] So, how do we deal with that issue, because it seems to me right now we're promoting them to the next level because they're social integration is the most important. But, is there not times for students with an LD where we should be saying, you know what, it wouldn't hurt to stay down here – with parental involvement, consent, and the team thinking it's the best thing – but I don't hear that happens very often anymore.

[Lynn] It doesn't; and I think again, I always say, that's when you have to have that discussion about the Individual Education Plan. What are the social, physical, academic needs of that child?

[Lawrence] Right.

[Lynn] In most cases, moving them on is okay, but you have to have supports in place, and you have to have resources in place. And you may have to reduce the credit load, you know? But we get caught up as parents: oh, he has to do exactly like the other kids do. No he doesn't. You know, because in the end, some people go to university, some people go to apprenticeship, some people go to work. So in the end, like for me, I think we have to look at the whole child. The homework is a good example, where you know, people said, oh well he has to do ten questions. I said, no he doesn't. He can do eight questions. You're not testing him on the number of questions he's doing.

[Lawrence] Right.

[Lynn] You're testing him on what is his knowledge that he's doing. And that's where the Individual Education Plan, that we really pushed to get hard in the legislation, is to really look at what is happening? What are the goals? How are we doing it? And, having those discussions, having the discussion, is he ready? If he's not ready, what are we going to do? What are we going to do skill-wise, intervention-wise to get him ready? Because, in a lot of cases, of course they want to be with their peers and they're better to be with their peers. But sometimes, emotionally and socially, they're not there. And so, either we've got to develop the skillset, so lots of discussions now about self-regulation skills, social skills, you know, even advocacy skills. We now, you know, develop advocacy cards so that kids can develop them. That's what we need to be doing. So that IEP is really crucial for me. So, it's not just a discussion about should he be promoted or not be promoted or move on, it's what do we need to do to make that smooth transition from grade two to grade three, wherever, and make sure everyone feels they belong.

[Lawrence] Yes, and your important point there, as well Lynn, because as you go through different teachers, both elementary and the secondary level, if you kind of think you're on a track, and as a parent, you're just stay on these rails, you forget that that new professional may be bringing something to the table as well.

[Lynn] Absolutely.

[Lawrence] That new teacher in grade three that wasn't there the year before, or guess what, that English teacher in high school really gets special ed. and they're going to do some things for your kid that are going to amaze you because they're going to bring their skills out, and parents often forget that because we get into a rut that's comfortable, and any change, we kind of want to pull it back to where we were, right. Rather than actually, let's be honest, if our kids are going to grow and mature, we need to let them embrace change themselves, because you and I are both aware how much resiliency is talked about nowadays. And that's part of advocating for your child as well, is not seeing every little buffeting as an excuse to batten down the hatches like we're under attack, but in some way helping your child embrace it and grow through it, because that's the life they'll face outside of school.

[Lynn] And that's our ultimate goal. I never wanted my kid to be velcroed to anybody. You know, I wanted him to grow and wanted people there to ensure his self-esteem was kept intact, and that as we moved forward that we were doing the best thing that in the end when he graduated that he would be successful and that he would work through the skills that he needed to do.

[Lawrence] I want to go back to something else you touched on earlier in the interview, and I think it's a really important thing and I want to flesh it out a bit. You said words along the lines of we need to recognize when someone's got a learning disability, they've got a learning disability. Obviously, as parents, when we first see the label disability we all run for the hills. I was no different. Hated that label, wanted to kind of bury it somewhere until I worked out that, hey, you know what? It's not going away. But, talk a little bit about why as an advocate should you embrace that? What rights and responsibilities does that label have that will assist a parent in this journey?

[Lynn] I think the one thing I would say, and I learned this very early on, everyone learns differently. But, if you have a disability, it impedes with some of the processes that you're dealing with in everyday life. And so, you need to ensure that the rights are there. So, whether it's the Education Act, whether it's the Human Rights Code, etc, and so for me, it was okay, he has a disability. That's all part of the grieving process. It's just like in the medical; okay, he has cancer. Not going to call it anything else but what it is; he has cancer. And remember, I had a son that had medical problems, and quite chronic, so lots of people wouldn't want to use the words of things that he had, right? Well, I'm not going to tell him it's something different.

[Lawrence] Right.

[Lynn] So for me, for learning disabilities is, yes Wade, you're a young man and you have a learning disability.

[Lawrence] Right.

[Lynn] It's not you're an LD person. You are a person first and then you have the learning disability. And in that word disability, there's a huge word called ability, and that's the piece we need to remember; that they have so many abilities, and we need to cash in on those. We need to build on those strengths and then we need to look at what are the needs that those strengths can help and then what else, interventions, can we do with that. I know as we move forward through the transition period; whether it's in post-secondary, work, or wherever, that if you have a disability you get accommodations from the Human Rights Code. You don't get accommodated because you learn differently. And so, often what happens, as they go through elementary and secondary, we go, oh I want accommodations in post-secondary. You know, he needs to have it; he's had it all these years. Well, if he hasn't got a diagnosis, just as if he didn't have a diagnosis of cancer, your GP isn't going to treat you. You go to the specialist.

So, knowing that it is a disability is not the end of the world. It's what you do with that information, and the disability, the profile, the diagnosis helps people understand, who is the learner.

[Lawrence] Right.

[Lynn] Who is my child? And you need to understand that. And if we don't understand that, in this very complex world that we have today, then we'll do a disservice for our children. And so, I'm a great advocate of the term is the term. It still has stigma because we as adults are struggling with it, and for our kids, they think they've got something terrible because we don't want to talk about it.

[Lawrence] Right.

[Lynn] And really, we need to talk about it.

[Lawrence] Yes, and that's so key. Because I remember the first time we had to talk to Jake, and I'm sure it was similar with you and Wade. Again, I didn't know the right language at the time, Lynn. I'd suddenly entered a new world, but interestingly, I hadn't entered it enough that I wasn't just adopting the school's language of he has a learning disability. So frankly, that was what Jake heard he had. As I learned more, we learned more that it doesn't have to restrain him. He went off to college; he's got himself a good career; everything worked out alright. We just had to learn to get the right strategies in place. And of course, the other thing I did for him constantly was made sure those areas that he was strong in, and in this case, it was sort of sport; that was one of the things he excelled at. I made sure he had success in life there so that when he was buffeted with the odd thing at school we could at least balance that out with, hey, guess what? You've got a rep soccer game this weekend, so we'll get through the week, we're travelling to Durham or whatever, and we'll go play the game.

But let's just talk a little bit about, I think you touched on the human rights thing, and again, every case is different.

[Lynn] Yes.

[Lawrence] But can you talk a little bit, Lynn, to the protections that the Human Rights Act in Ontario actually gives our kids? And when a parent may want to just be aware of them; not necessarily go out and start a human rights claim, but let's be honest, they do, when we're looking to advocate for our kids in the school system, as you said, show me the legislation; knowing those rights is an important part of growing your advocacy. Would that be fair to say?

[Lynn] Absolutely. You need to understand that. So Human Rights oversees everything else, you know, so whatever the Education Act says, etc., and medical, health, recreation. The key with Human Rights, you know, people would say to me, you know when they were angry, I'm gonna sue the board. I'm

gonna sue that principal. I'm gonna go to Human Rights. And I said, well let's just think about this for a minute. Once you start going down a path of Human Rights, it takes a lot longer. And we go down a Human Rights [path] because we really feel that we have tried everything else and we're trying to break down that systemic barrier that's in the way. So for the Human Rights Code, it could be in the principles of accommodation. It could be the welcoming environment of students. It could be the process of accommodations. It could be the right to confidentiality. So Human Rights really helps look at situations and say, okay yes, you know, if you feel that your child's needs are not being met, but you're involving lawyers, you're involving another third party, you know, that is going to pull out everything, and sometimes that can't be resolved for years. I mean, the families who've gone down the Human Rights process has changed some of our legislation, absolutely. And it needed to be changed, but it's changed now, and so now, I feel strongly that Human Rights is the very last resort. And I would be going there if I felt that my child's life was on the line because people were doing things that were totally inappropriate for their self-esteem, not doing their accommodations. But as parents, we think that certain things should happen, you know, because someone else has told us that. Or, we think that ourselves. You need to do your research. But I think, I'm glad we have the Charter of Rights. I'm glad we have the Human Rights Code because there are times when we really need to go there. When I look for people with learning disabilities, I think we have enough legislation in place. Do we need to still do more training? Absolutely. You know, for our new teachers coming in. Do we still need to get people to understand what equity is about to ensure that, yes, we have an invisible handicap, but we have rights, and that includes our accommodations. And that includes to make sure we have the technology. But the legislation is there if we need to go down that path, but it is a very long process, and in most cases when I've been asked to get involved with some things, I've been able to resolve the issues at the school board level and not have to go the next route. But if I felt that it wasn't being resolved, definitely you would let parents know that they have a right to go down that path.

[Lawrence] And I think it's so important Lynn that, as you say, it's not the first recourse; it helps to guide you. But I think the other thing is, I think it's fair to say, in the Jeffrey Moore case in Vancouver is probably the most important in recent history, but everyone should recognize that by the time that thing got to the Supreme Court, Jeffrey had left school ten years before that. So the reality is that if those roads, yes you may make systemic change that may benefit others, but you're probably not going to resolve your child's issues.

[Lynn] No.

[Lawrence] Because the courts and Human Rights cases, by their nature, take years and years and years to actually come to some sort of conclusion.

[Lynn] And I always say, I would rather have that money spent by families in schools using it to find the right interventions and the right accommodations in the school system so it can be dealt with because they'll have learned, okay, we can now use this for other kids.

[Lawrence] Yes.

[Lynn] And sometimes that's what has to happen. You know, for people in my generation, I was a pioneer. I'm okay with that. You know, if it made a difference, not just for Wade, but for other students, but for parents, you're concerned about your child.

[Lawrence] Right.

[Lynn] Absolutely. And I think having our organization, the Learning Disabilities Association available to you makes letting you know you're not alone.

[Lawrence] Yes, absolutely.

[Lynn] And I think that's important.

[Lawrence] And I think the other thing, I'll give LD@home a quick plug, is the other thing that confused me Lynn, because we do it in the field so much, is the acronyms fly at a rate of knots. Parents listening to this should know there's a glossary on the website and it was one of the first things I insisted on because, I was talking actually to Kelli on the podcast yesterday, one of the things that's so interesting is I had a friend of mine, and who, because of what I do, said can you look at my child's IEP? And when I read it Lynn, they kept saying, I've got a really simple question but I'm confused by something. And I'm like, okay, what's that? She said, well they keep using the word at but they put capital A capital T. And I went, yes, that's because it means assistive technology and things that simple can completely miss a parent because the parent doesn't realize. So we're always talking to educators about please explain the language, and for parents, again, back to educate yourself. Know what the IEP is. Know what an IPRC means. Know what rights the Act gives you. Get that as your background knowledge and then when you advocate it's going to be much easier for you.

[Lynn] The one thing I learned too is that so often people would say oh don't tell the school about this; don't share some information, and I would say, why? You know, if this is going to impact on his learning then I'm going to share the information. So it works both ways, you know. So if I had jargon because of his medical health issues and how that would impact, then it's my job to educate them, you know, along with other medical professionals. And it works the other way. And we do use a lot of jargon and we're trying to change that, you know, so that we're not using as much jargon, but I used to say to parents, I used to say to my husband, if you don't know what IPRC stands for, ask. If you don't know what an IEP is, ask. If you don't know what an OSR is, ask.

[Lawrence] There's no dumb question. The dumb question is the one you don't ask.

[Lynn] Exactly. And the one that you feel, oh I guess I should have known that so they're thinking I'm stupid too, no. You know, ask those questions. And I always say, when you go to a doctor, do you just agree with everything they say to you? I hope not! You know, because you have to know your own body. It's the same way with your son or daughter.

[Lawrence] And I think it's so important Lynn that it's really, I sometimes say to parents, it's like being the captain on a sports team. The teachers, your son, you; you're all on the same team and at times you need to drive that and be the captain and organize and give some direction, but you're still looking to win as a team.

[Lynn] Yes.

[Lawrence] You won't win solo in this game. It just doesn't work that way.

[Lynn] One of the phrases I use a lot is I'd rather be part of the solution than part of the problem. You know, so, if I'm seen as that aggressive parent who only has one view and is not willing to take into everything else, then that's not what I want for my son or daughter. You have to be that role model. I also used to say to parents, to be a great advocate you have to have a sense of humour because there's some days where, really, you know, and you also have to have a support group. You also need to know that you know your child better. But make sure you do. Make sure you're realistic. Make sure you're reasonable. Set goals. Develop confidence in yourself, because people would say, oh I'd rather you do it Lynn. And I'd say, no. You know what? You've got to learn. Let's teach you. What are those skills you need? Problem solving skills, conflict management, communication. Being a parent is a tough job.

[Lawrence] Absolutely. No one trains us for it.

[Lynn] And being a parent of a child with a disability is another layer, you know. And how we connect to making sure that we understand who that child is. And you'll go through different processes, especially during transition and different grieving; oh my god, they're going to still ask me these questions all over again? Yes. You know, I would have my little journal, you know, of different things that people needed to know.

[Lawrence] Sorry Lynn, but I'm going to stop there because there's a really important point you made there and I just want to emphasize it here in the recording. Be organized.

[Lynn] Yes.

[Lawrence] One of the things we do as parents, not very well, is have lots of discussions with various people and a month later, did I say that to so-and-so? So there are some tools on LD@home again. We've just put some parent logs so you can actually write this down, put it in a folder. It's a PDF file.

However you do it, write it on your phone, make some records because you and I both know this is a long term thing. You're going to be at this for years and years and years and what you said to someone in grade one may not seem important in grade three, but you know what? That's all the background and history that's taken you to where you are today.

[Lynn] I always say to Wade that he's created who I am because my memory is very intact.

[Lawrence] And the other thing you commented on. I just want to bring it up to emphasize it Lynn, make sure you're talking to your child because let's be honest, we live in a world where, and I know this from Jake's perspective with me, I could've battled to make sure he got academic credits and went to university. That actually was never my boy's ambition. So what we worked out as he got a little older was, Dad, I love working with my hands. I'm very visual. We looked at motor mechanics for awhile; he went down that road for a while. That didn't quite work out. He's now a trained chef, went through George Brown's program, and he loves it. But the reality is, that kid didn't want to go through university. Me as a parent pushing to get him down a certain road without making sure I'm involving the child, and unfortunately I see it too often where a parent gets in their head their child's future, not the future their child wants. So you have to make sure you have those discussions as well on a regular basis.

[Lynn] Absolutely, because I can't tell you how many teachers were shocked when we said we really don't know where he's going to be at 18.

[Lawrence] Right.

[Lynn] But we do know that his self-esteem has to be intact. We do know that he needs to have skills. And we do know that at some point he needs to work. So what is that going to do? He went to post-secondary, he went to college. You know, that was the right route to go. But if you don't have those conversations, and of course, media will sometimes say, everyone should have a post-secondary degree. You look at that; a lot of them will have university degrees and then they go back to getting a college degree or going back to an apprenticeship. There's nothing wrong with that.

[Lawrence] You only have to look at Lynn how many graduates are out there unemployed right now and the skilled trades are crying out for people. And I'm not saying our kids should always be pushed to a trade, but what I'm saying is sometimes parents close off avenues instead of really thinking about the full picture.

[Lynn] And that is where you have to be reasonable and realistic and really know your child. Like, are we setting them up for failure or are we setting them up for success? And, you know, we have to always involve the child. I feel strongly about that. I feel that you need to ensure the family has a good support system, whatever that will look like. Do I go to a cocktail party and everyone's talking about learning disabilities? No. Do I go to a family event and they're all talking about learning disabilities? No. But they

know if something happens, could be because of this and then what are we going to do? So it's being open about it. It's really looking at the value of relationships, no matter. We still are in contact with our first psychologist, his first teacher, his first speech…you know, they're still involved, you know. They connect with him every year.

[Lawrence] Well, and the other thing parents have to know as well Lynn, and I talked about being the captain of the team. To carry that analogy on, initially you're on the field. Over time, you're going to become the coach on the sideline. And you've got to actually work that transition out as well because if you're still playing when your kid's in college and you've not allowed them to take the ball and run with it, you're going to have issues. Because we ultimately have to produce functioning adults who can go into the workplace, go to where they need to go to in life, right? And that doesn't happen if you never give them the baton.

[Lynn] The one thing that I've been dealing with a lot lately is that, you know, they'll say you go to post-secondary work. Well, you know, the student or the child, the young adult has to speak but sometimes they need an advocate.

[Lawrence] Right.

[Lynn] So, I may be his Mom, but I'm not there as his Mom; I'm there as his advocate. Or you bring in someone else from the organization. And the same way with post-secondary. Well we can't have the parents come and tell me about their kids. I said, well, let's look at that a little bit differently. Maybe the parent is coming as an advocate because the child's needs are not being met and maybe the child, the young adult, has asked for assistance.

[Lawrence] Right.

[Lynn] They know, they put their advocacy card, they know their strengths, they know their needs, they know their interests. But they don't think they're being listened to. So let's just change the little circle a little bit. They're there as an advocate. I don't go in as Mom. I'm there as his advocate. It's very different. But you're doing it with them.

[Lawrence] And again though, see, wearing that different hat then, by you saying that, you're also saying now, as a parent I'm disengaging my emotions.

[Lynn] Yes.

[Lawrence] I'm coming in as a clear-headed advocate to talk about this student's needs and help them to get their voice heard. That's not me going in as a parent and banging the table, right.

[Lynn] Exactly.

[Lawrence] That’s the huge difference.

[Lynn] That’s the difference, and I’m doing it with him, you know. And so you develop a plan. So when you’re doing advocacy, it’s prepare, plan, act and evaluate.

[Lawrence] Right.

[Lynn] Stop. Think. Evaluate. Check. Act. Check it out. You know, that’s what you have to do. And so, whatever that is to make that young adult or that kid feel in control of their own needs is the best thing we can do as parents.

[Lawrence] Okay, I mean there’s been lots of fantastic discussion today Lynn so one last question as we come to the end of our time today: if you could give parents one word of advice; so you’ve given lots of advice today, but what’s the one thing that is most important every parent hears from you today. If I’m starting this road as my child’s advocate, and again, we’ll have parents in various stages, but let’s focus on the beginning because some people will alter their style based on hearing this. But I’ve just got my diagnosis, I’m on the start of this road. What’s the most important thing I need to bear in mind?

[Lynn] That you can’t do it alone and that you have to start working with other people. I think remembering to be a role model for your child because you will then teach your child how to be a self-advocate. That’s always been my prime responsibility is to ensure that Wade understands how to be his own advocate, and the value of relationships, no matter who they are that are involved with your child. Say thank you, just as much as I expect them to thank me. Getting involved with the organization. It’s not the end of the world and move forward. And there’s so many success stories out there for our kids.

[Lawrence] Absolutely. Lynn, thank you very much for your time today. Thank you for your insight. Ladies and gentlemen, as you’ve listened to this, I’m sure you’ve learned lots of things and probably have lots of other questions. Your local chapter is that point where Lynn says about the organization. Find your local chapter on our website, either LD@home or LDAO.ca and give them a call. They’re there to help. They have people who have done this before and they can help guide you through this. This has been TalkLD. I’m Lawrence Barns and until next time, goodbye.

[Music]