

Lauren 00:10

Welcome to our LD month mini-series of The LDA Podcast where we're bringing you conversations about support, education and advocacy, LDA's main missions. Today, we're talking to PA State Representative Dan Miller, and LDA leaders and advocates Bev Johns and Daphne Uliana about how to best advocate to policymakers.

Dr. Monica McHale-Small 00:31

Good afternoon, everyone. And thanks for joining us today. I am especially excited about today because one of my main reasons for becoming so involved with the Learning Disabilities Association of America is because it has been so long active in policy advocacy on behalf of individuals with learning disabilities. For those of you who do not know, LDA has been around since 1963. And in fact, some of the founding members of the Learning Disabilities Association of America were instrumental in making sure that learning disabilities was a category that was included in the IDEA when that legislation was passed. So in other words, without LDA probably many of the educational and workplace advances for individuals with learning disabilities would not be in existence today. And today, we're going to be talking about how it is that you become involved in policy advocacy and may develop relationships with policy advocates and people who are active in this field. So with us today, we have Dr. Bev Johns, who has been an active member of the Learning Disabilities Association for many, many years and has been a state president and state president's representative. She's active in LDA's Healthy Children Project, which seeks to ensure that all children are able to live and learn and develop in environments that are free from environmental toxins that we know exacerbate learning disabilities. She has over 35 years of experience in special education and public schools in Illinois, and she is now a retired professional fellow from Mary College in Jacksonville, Illinois. We also have with us today, State Representative Dan Miller from Pennsylvania. Dan was elected to the House of Representatives and Pennsylvania in 2013 and was elected as chair of the Allegheny County House Democratic delegation in 2019. He serves on the Education Committee, the Judiciary Committee, the Labor and Industry Committee, and the Human Services Committee. He is co chair of the subcommittee on special education and the Blue Green Alliance caucus. He is also a member of the autism and intellectual disabilities climate, early childhood education, firefighters EMS, LGBT equality, hope, and steel caucuses. So he has quite a lot of advocacy work under his belt. And then finally we have Daphne Uliana who is co chair of LDA Public Policy and Advocacy Committee. Daphne was instrumental in getting the dyslexia and early literacy intervention pilot program signed into law in Pennsylvania. And she was inspired to get into advocacy work by the struggles of her own three children who have dyslexia, and her 25 years of political experience. Daphne has been a very passionate and strong advocate for individuals with dyslexia and for science-based reading instruction in Pennsylvania. So our topic today is about building relationships with policymakers. And I wanted to ask each of the panelists: who are the policy makers, in your opinion, that are most relevant to students with learning disabilities?

Dr. Monica McHale-Small 04:10

Okay, I think that's probably dependent upon in what state you are in whether you're working on a state issue or a local issue. And what we often learn is that sometimes the people who are driving policymakers are not always the policy makers themselves. So when you are looking at a bill, granted, you need to look for a legislator or multiple legislators who share the passion you have for that issue.

For instance, we just completed last year now and are working on the regulations for a bill that provides interpreters for non-English speaking parents and IEP meetings. And we found a legislator who was as passionate about the topic as we were, and she was extremely helpful. So you start with legislators who have an interest in the topic that you're wanting to introduce in the legislature, you obviously then you have to deal with staff, and members of legislators as well. And you need to get to know them well. And then I always say to people, in the legislative process, you have to know your friends, and you have to know your enemies, because you have to know what the other side is saying about an issue. And if you don't know that, you're not going to be able to combat with counter information, so that people understand the scope of the issue. You also have to know the scope of the power of some of the lobbying groups that if you're working on a state issue, the scope of the power of some of the lobbying groups in your state. And the other thing I always say it's easier to kill a bill and get a bill through the whole process.

Dr. Monica McHale-Small 06:18

Dan, how about you, who are the policymakers that you believe are most relevant to students with learning disabilities?

Dan Miller 06:25

Like Bev said, it does depend a bit on what your what your question is. So on the local side with it, superintendents are where I find is the most direct path to change. School directors not so much. It depends on how they function. Some school directors are a little more involved, others will adopt a hands off approach, and largely rely on the people they pay full time to make those decisions for them. So it depends on the nature of your school board and how they operate if you're looking for a legislative fix. First off, if it's for an individual problem that you're time sensitive to, most likely that is not going to help you. If you're bringing up an issue that systemically you want to see change that would better things to come, then that's most likely the way to go, the approach you take with a legislator. And the idea, the best thing for you to do is if you're going if you need to go this route, find a legislator with some interesting experience in some way. Find them on the right committee to advance the bill, go online, check out the State's website, whether if it's your legislator, great, but no matter what, look to see who's close to you, and go that way. And then hopefully find somebody who's on that committee that can help. The other thing too, I would suggest to you on the individual side is if you are looking for a larger systemic change, than most likely there are many others like you, that could be in your district. But most likely, it's your county and state, there are families who are going through the same thing. That's where some of your organizations like this one can help sort of galvanize. There's no point in you trying to reinvent the wheel, or for you going off and sort of like squawking as long as you can in a corner where other people are ready to sing with you. So I would also look to partner up as best you can, with organizations that are tightly connected to your particular focus or even general focus and to use some of their ability to magnify the concerns and to galvanize a larger regional or statewide approach to moving legislation in some way.

Dr. Monica McHale-Small 08:31

I want to also thank you for mentioning superintendents and school directors because I think sometimes we only think of those folks for individual student advocacy. But they can also be very much involved in policy at the local level in Pennsylvania, or local control space. So while there may be some

guidance that comes down from our Department of Ed, there's an awful lot of wiggle room. And so that's a good way to kind of dip their toe in the policy advocacy world is by working very actively with your superintendent and your school directors. Thank you for that. And Daphne, how about you? What are your thoughts about who are the important policy makers?

Daphne Uliana 09:10

So I can't add to too much because I think Bev and Representative Miller really said a lot there. But I think it's always important to start with your your own legislator and introduce yourself to them just so they know that you're there and what your issue is about and you never know where they might lead you and help you. I agree about finding out who's on the Education Committee. I think it's important to also find out again, it's not just, you know, policymaking. There's legislators but there's also, for example, in Pennsylvania, we have the State Board of Education and they have monthly meetings and they're open to the public and free in fact, the one going on and Pennsylvania is happening today right now. And that's always interesting to really learn about the process and what people are thinking and it gives you a picture of a higher level of what the department is thinking of what are their bigger pictures and so you can sort of see where your your issue fits in. I guess I have two just quick other thoughts about it, it's important to, again, know who's on your committees and then do your research before you go into to visit with someone, your legislator, or someone on the education committees understand where they're from, understand what you can about them, their bios. I hate to go into a meeting when you're really not familiar with who you're actually going to see and talk to. I think that's really important. And maybe we'll get to this later, Monica, and one of your other questions. But, you know, it's never an easy process. It's long sometimes, and you get frustrated, but you have to just keep moving forward, you always have to think about the cost and money because as much as we don't want to believe everything is about money, sometimes a lot of things are about money. And you have to understand that you can't ask for all these things and expect you're gonna get them if it's costing millions and millions of dollars. We can hope. But it forces us all to think seriously about what it is we're asking for. And what's really important.

Dr. Monica McHale-Small 10:59

Here's one from Brett Moyer, and this is directed to Dan and says: You mentioned stories of people within the IDD community that keeps you going. What format do legislators prefer in receiving personal stories? Talking points, video, brief printed testimonials...We want to make it easy for legislators and create shareable content. So what would you recommend?

Dan Miller 11:22

The key is personal, right? You got to remember that on the face of it, I've never met a legislator who won't agree with you, with what you tell them. Not on these issues. They will all agree with you, they will likely take pictures with you. Very nice. But will they vote with you? Two different questions, right? So your personal stories is what can transcend some of the other considerations that come into play. Keep in mind that the majority of people don't have dyslexia, or whatever the diagnosis may be, there is an educational necessity that you need to provide. And the more personal you can make it, which can be hard, but the more personal you can make it the more likely you are for that story to stay, so that they won't need notes. When they go to the floor, they will picture you, your child, whomever. So whatever you can do personally. I do like, by the way, I do think some of the videos are kind of coming around

more than they used to obviously, because of the COVID environment, I think they can be very good, I think they can be very compelling. The face to face, of course is always the best, that can be difficult, but the face to face is always the best. Otherwise seeing is always better than reading. Look to many of my colleagues defense in this regard, we get a lot to read. And it is sometimes difficult to process everything, especially when they may be unfamiliar with terms. So in my opinion, how you can use your face is the best way to relay your message, whether that be in person, or whether that be in video. And every one of these reps, myself included, we do pay attention to the little Twitter-verses of things, Facebook Messenger, you know, things that we get. So I do think social media does make that easier for you to do.

Dr. Monica McHale-Small 13:11

Great answer, thank you. Daphne or Bev, either one of you want to build on that or comment?

Daphne Uliana 13:17

I do think face to face is always good. And just remembering too that representative Miller probably sees so many people in a day and has so many phone calls. And so when you do go visit, be short, concise in your story. But you know tell the story and have it be meaningful, but just remember, they have see a lot of people and you got to get your point across quickly with emotion but quick and try to get in and out and get their support.

Dr. Monica McHale-Small 13:46

All right, Daphne, I'm going to direct this one to you first, because I know for a fact that this was something that you grappled with. So Lyn McMurry has asked: Who helps us parent advocates write the proposed bill?

Daphne Uliana 14:00

My experience has been, we worked closely with Representative Nielsen and Philadelphia. And we would sit down and talk to him. He had initially introduced some legislation and so it was a little bit easier for us to take that piece and sort of rewrite it...we we didn't rewrite it, we suggested changes. And then he took those changes and took them to the what they call the Legislative Bureau, and they actually write it into the legal speak. But the other thing is to again, find a legislator that or a senator that is friendly to your cause. And sometimes it's just ideas and to sit down with a legislator and say these are what we're thinking about. These are the ideas and they can manage to get it written into the legal language.

Dr. Monica McHale-Small 14:49

Okay, Dan, Representative Miller, do you want to add anything to that?

Dan Miller 14:53

No, look, it's you know, I think Daphne talked about the, it's sort of like a back and forth discussion. I think I'm like maybe number five in the House with bills this term, right? I tend to do pretty good amount of bills. Overwhelmingly, I write them. So doesn't mean we don't work off some ideas that people come up with. But overwhelmingly, I personally need to know every line of my bill. So I don't like surprises. And I don't like writing something that's wrong. So Daphne mentioned the LRB, the Research Bureau,

they sometimes miss your intent on a couple of things. So as good as they are, and there are some great attorneys there who are helping, they don't know every aspect of every issue that that comes to them. So there's no doubt that once a legislator agrees with you, or you agree enough with that legislator to support their bill, you do have to check it before it goes. You don't want to do a lot of cleanup work on the committee level, or things that will like, make it look like more of a headache to a chair, who's just like, 'is your is your bill ready for primetime? Or is it not? And how many fixes do I have to make to get that bill through?' So you want to streamline it, and be where you want it to be before you formally file.

Dr. Monica McHale-Small 16:22

Okay, Bev, I see you nodding knowingly. So I think maybe you want to chime in here,

Bev Johns 16:27

Literally, because you have to have specificity in the bill. And it's really gonna capture what you wanted to say. And you do either work with your legislator, or your legislator may assign a staff member to work with it, and you get the ideas worked out. And then in our state of Illinois, it goes to the to the Legislative Reference Bureau, and then you look at the bill again, and you make sure that it really has the intent of your language. And then even once you pass the bill, and the governor signs your bill do not think it is over. Because for instance, when we were doing our legislation for interpreters for non-English speaking parents, we had to work with the Illinois State Board of Education, and they had proposed regulations, we had to comment on those proposed regulations. So it isn't always over. When you get the bill passed and signed by the governor, there are a lot of steps in between, and you have to persevere. And while we're on the topic of pieces of legislation, my best piece of advice also is you read the entire bill, you do not rely on people telling you what a bill says, you read it yourself. And every line in that bill is important. And we'll never forget this has been many years ago, I was assigned the task of reading a piece of legislation that most people thought was just innocuous, it didn't mean anything, until you got to the last sentence in that bill. And it said repeal Article 14 of the Illinois School Code. Now I knew Illinois, the Article 14 of the Illinois School code was special education. So one sentence would have wiped out special education. You have to read the whole bill, you don't rely on what other people tell you, you want to make sure that there is clear intent on what you want. And then another point is you have to know your bottom line, you have to know what you are going to sign off on and what you are not willing to sign off on. So you got to know that and somebody may say 'Oh, well, I think if we just put this in there.' Wait a minute, let's read it. And let's make sure that is a good thing to do. Because it might not in fact be a good thing to do.

Dan Miller 19:17

Well, and if I could real quick and by the way, you said reference it was referenced not that Research Bureau, thank you Bev. But know your legislature at some point, too. Okay, is one year suggesting something that is really something that can work right now? Or are you putting down a benchmark, something that would be part of a long-term campaign, that you recognize that the current makeup is not going to do? But you want to get this out there for a variety of purposes. Some of the bills I write I know that the majority in Pennsylvania are not going to pass right now. It doesn't mean that it's not the right bill, doesn't mean that the issue is wrong. And it just means that we're going to have to write it, and we're gonna have to talk about, we're gonna have to argue about it until we get to a position where we

can start changing some minds and addressing some priorities. So I would recognize that there are sort of two different approaches to what you decide to do. And there comes a point where your compromise efforts may bring you back too little. And you have to also be cognizant of that. It's kind of like the, the old man and the sea, you caught that fish, and you're going to do everything you can to bring that back to shore, but how much of that fish is left when you get there? And then you have to decide, are you satisfied with what you're doing when you get to that point?

Dr. Monica McHale-Small 20:36

Good advice. Thank you. Okay, so let me say we do have a question that I want to get to. So this is from Judy McKinley, and she has a concern that students with specific learning disabilities frequently get left out of the conversation when we're talking about dyslexia. In California, students identified with dyslexia are generally privately assessed versus an assessment by a school district, which would not identify dyslexia. So that's not so much a question more of a comment. But I do think that it's one that we should address. And, you know, I'll just start by just reminding everyone that, you OCERS, the Feds did put out a letter in October of 2015 that, noted that dyslexia is a learning disability, and that when appropriate, we should name those learning disabilities when we are evaluating children in public schools or developing an IEP, so not just dyslexia, but this dyscalcula, dysgraphia. Daphne, would you like to jump in there?

Bev Johns 21:43

I would say that this is a problem, certainly, that we are facing in the state of Illinois as well, and that some school districts unfortunately, do not believe it's their responsibility to do evaluations when the student may have dyslexia. However, that is, in fact, the school district's job to do that. We are just seeing and I think this is happening, a lot of places across the country where there is reluctance to do evaluations. And that's very unfortunate, because we are waiting too late for some children to be evaluated. We continue to have to get the word out about this issue. And we're just seeing too many parents have to have independent evaluations, when the school district should be doing the evaluation.

Daphne Uliana 22:41

Well, and people get caught up in the word. So right, the parents will say, I think my child has dyslexia and the school district says, well, we don't test for dyslexia.

Dr. Monica McHale-Small 22:49

Right.

Daphne Uliana 22:50

They do. I think some of it is trying to educate parents, and then maybe, you know, in school districts too about interchangeable, you know what that word means how it fits into the SLD category, things like that. I'm not really even sure how to correct it other than just to keep talking about it, and to keep telling people, and when I have a parent call me and like they do, they just don't call it dyslexia. And then the parent gets so angry, right? And now you've already started off this horrible relationship badly when you feel like the school districts lied to you. Now granted, there are some people in that school district world who still don't understand, but I, you know, they can do a lot. They just don't always use the word dyslexia.

Dan Miller 23:32

My advice always is, I don't give a damn what the school district says. I couldn't, all due respect, I don't care what word you use, what word you don't use. If my, if you have a child with dyslexia with it, we need to find a way to ram those services down the throat of that school district. That's just straight up. And I love it and appreciate the schools in so many ways with it. But I don't have the time for that kid to mess around with whether or not you want to call it one thing or another. There's only so far I can go with education, with educating you, the school district, about the job. If your school board member can't tell you what an IEP stands for when they're running for office, don't vote for them. Right? If your school board member cannot tell you what the differences between an IEP and a 504 plan, don't vote for them. So if you can't understand if you can't bring that to the table, when you come to ask for my vote, you are running for the wrong office. And I don't have a time to have to educate you on what dyslexia is or what an IEP is.

Dr. Monica McHale-Small 24:35

Yeah, and I don't want to take away valuable time but Daphne is right. I could go on and on about this, but dyslexia is a learning disability. Right? We know much more about learning disabilities since IDEA was first asked and when we have names for learning disabilities, we should be using them. But we are almost out of time. This has gone amazingly fast. And there is one other question I want to get to here from Tracy Gregoire that: at what point do you recommend getting press involved to share a story, to use that as a tactic to get pressure or policy to be passed?

Bev Johns 25:12

Well, that's a topic that is near and dear to my heart. Because with the Healthy Children Project, we have had to go to the press on a number of occasions. Do you have to go to the press? Sometimes we've gone to the press with Healthy Children. And frankly, when all else fails, go to the press. That's the bottom line, because most people do not like bad publicity. And bad publicity gets out and everybody is more aware of the extent of the problem.

Dr. Monica McHale-Small 25:46

Representative Miller, do you want to jump in on that?

Dan Miller 25:49

I think that that is right. In that regard, I can't tell you of a personal scenario where I've seen it be incredibly successful locally. But again, I guess my point about all of this, really, is that advancements and special education in particular have only come because parents have demanded it. That's only been the case. A lot of moms, there's some good dads been working hard too. But it's very hard to separate the advancements over the last 20 plus years roughly, in special education without the stories of parents and in particular, a lot of moms who go forward and do anything possible to get what their child is entitled to and their child deserves. The only thing I would say on that is in COVID, unfortunately, we're going to need to do more. And during this type of time, again, whatever your problems were before, they are likely worse and more challenging now. And so that's going to require us that while we look for a lot of patience and school districts, and I know there's a lot of hard work being done by some great teachers and so forth, the reality of it is that we cannot have that those

children with any diagnosis bear the brunt of the shortfalls of education during what is this COVID period. And I fear, especially here in Pennsylvania, that that is going to be the case, that is the case. That was the case in the spring. I fear it is a bit of the case now. And I'm concerned that it'll be the case for the entire 2021 school year.

Dr. Monica McHale-Small 27:20

Okay, this went incredibly fast. Any closing comments?

Bev Johns 27:25

I just would like to close with advocacy is lifelong work. And we have to continue to advocate because we're advocating for the children who have the immediate problem. But we're also when we're advocating are advocating for a lot of other children out there who may need the same or similar services. We can't give up. We have to invigorate ourselves every day with advocacy work.

Daphne Uliana 27:58

I'll just say quickly, I would agree, keep going. Sometimes you have to take a break, take a breath, step back. When someone throws a barrier, you got to figure out how to get around it, above it, around, on top of it. And it isn't always easy, but it's so worth it in the end. And it's just so worth it. And so incredibly important.

Dan Miller 28:23

I will just say that, look, we all stand on the shoulders of those who came before. And we have to be sure that we do the same for those who are coming.

Dr. Monica McHale-Small 28:33

Well thank you all for sharing your expertise with LDA today and with our audience, I know that we're all very, very busy so that you took time out of your day, especially you Representative Miller, which I'm sure you have incredible amounts of responsibility. So thank you for giving us your time today. And if you are not already a member of LDA everyone, please make sure to join. It's a great organization. Thanks.

Lauren 29:16

Thank you for listening to the LDA podcast. Our theme music is a little idea by Scott Homes. Learn more about Learning Disabilities Awareness Month by following us on Facebook, Twitter, Instagram and LinkedIn. And for more learning disabilities resources, visit lda.org