



Varied Ideas of Inclusion: Studying Parent and Teacher Perspectives

Lauren Clouser:

Welcome to the LDA Podcast, a series by the Learning Disabilities Association of America. Our podcast is dedicated to exploring topics of interest to educators, individuals with learning disabilities, parents and professionals to work towards our goal of creating a more equitable world.

Dr. Monica McHale-Small:

Okay. Hello, everyone. I'm Monica McHale-Small, and I'm the Director of Education for the Learning Disabilities Association of America. Today I am welcoming back Professor Julia Carroll and her colleague Dr. Angela Thompson. They're going to talk about another paper that was recently published: Seeing, Being Seen, and Being Able to See Dyslexia in English Schools: Parent and Teacher Perspectives. I think this paper is going to be of a lot of interest to parents and teachers as well, so I'm going to hand it off.

Dr. Angela Thompson:

Thank you very much indeed, Monica. I'm Dr. Angela Thompson. So this research work sort of came out of my original PhD studies. And you sort of asked me informally beforehand what drove the actual research. And I have dyslexia quite severely, as most of my colleagues who work with me will attest to. I have two children who have dyslexia, and it was actually trying to navigate through that school system. You know, I started off from a point of not having any education in this area and then sort of acquiring education first through a single module in psychology, and then that turned into the degree that turned into the PhD. But looking at why it was so difficult, you know, that you kind of looked at it and you thought there's an awful lot of research about dyslexia and the kinds of things that can help, and yet the outcomes are so bad. So, what's happening between this research and what's happening in a classroom and to an individual child, and that was really the driver forward.

And it was also a bit of me that was getting a little bit cross with the teacher-blaming thing that was going on. I had a mother who was a teacher, so I had a little bit of sympathy for them, even if I was having a bit of trouble with actually dealing with the school system. And as far as I could see, you had a lot of teachers who were working very hard, and they were being blamed if the child didn't make progress. And so then that kind of set up a scenario where then the teacher would be blaming the child. And it just felt like this was a fairly unhelpful, unhealthy kind of framework. So as a parent, I kind of knew that we had a lot of information. As a parent, you see

your child, you see how they develop, you see how they develop over time, you see what their interactions are. When they go in and see certain teachers, they're okay, and when they see other teachers, they're not.

And so I thought, well, actually, parents are not represented in this literature at all. So everybody's been asking how to improve dyslexia, but asking the people who actually deal with this on a regular basis, on a day to day, the parents. And then the other thing that was really missing in the literature was looking at the school structure. It was kind of this big invisible elephant. So everyone was looking at the child and how you could deliver interventions and how you could possibly change the classroom and how you could do support, but not actually looking at the structure of education itself. And so those were the kind of two drivers that sort of drove me forward. It was a kind of personal story. And then it was like, guys, I think you've been asking the wrong questions in the wrong way, basically.

And, you know, that, that kind of showed, you know, in the kind of very early stage, as I gathered all of the kind of literature that I could locate, that wasn't all of it, but a big substantial portion of it. And it fell into kind of like the scientific stuff, the cognition, the testing, the processing issues. And then there was this really quite small amount about sort of the experience of having dyslexia. It was very small, very evocative. But the problem with the qualitative, evocative, emotional stuff is it doesn't actually really tell you how to make any changes. It recounts the story, but in recounting the story, it's almost expecting the reader or the teacher or the policy maker to actually formulate their own ideas about how to deal with that. And then the scientific stuff might tell you this intervention works, this one doesn't, this one's partial, but it doesn't tell you about that experience. It doesn't tell you what it's like.

It doesn't tell you who's effective and what else gets in the way. And so these two weren't actually speaking to each other. And there was some work about classrooms and things like that, but it wasn't really looking at the whole structure. And so that's where I kind of thought, well, actually, what are the structures in education, and how are they leading and precipitating disability, and what do parents and teachers try and do about it? And so that's how I then formulated the work. But it was quite a process to go through that. You know, there wasn't anything out there. It had to kind of be developed and there was just this sort of morass of data I had that I had to try and sort through and try and work out how this was going to get structured.

Dr. Monica McHale-Small:

Well, that's a perfect lead in. Can you talk a little bit about what was that structure? How did you go about that question?

Dr. Angela Thompson:

Well, I started off, funnily enough, thinking about having a checklist for teachers. So the original work I came in was about a checklist for teachers and I had a kind of structure about what made for efficient education or evidence based education. So I set about interviewing a set of parents and these were parents where their children, there was kind of like a reckoning, organized level.

They'd been acknowledged as having dyslexia, literacy difficulties, they had statutory support. So it was kind of easier to pick out the story from them. And so I interviewed them and then I looked at this and I think that model of mine doesn't work. You started on a PhD and then your core idea isn't actually going to work. You're kind of like, oh, help.

And I had a choice at that point. I could have sort of carried on with that and I would have finished a PhD and I would have produced a checklist. But actually that wasn't going to ever be the answer to the question that was really burning, which is, how do I make this better? How does my work improve the possibility of children getting better education? And so I started to then look at like, well, what's going on? And so what you had was children having very variable access to education. The parent-teacher communication could be a variable and that depended upon it. That knowledge was very patchy. So there was a kind of set of findings from the early one that then actually led me to that issue of looking at structure and agency and from that work, and then I went and gathered further information. So it was very much a rolling research. You know, you'd do a set of interviews, you'd then go and analyze them, you'd then work out what else you needed, which other sort of participants, which other part of the story was missing.

You go and interview them, you'd work out the next bit. And so it rolled on over quite a period of time. And there was a longitudinal study in this, so there were people I interviewed and then four years later interviewed again. And so what you saw was that teachers essentially looked at the child in terms of the class, so their sort of perspective was at the class level. And you saw that it was kind of like education was like a series of segments next to each other, and they were kind of like single self contained units. But parents actually saw the child across the trajectory of time, and so they saw the difference between one year and the next, and they saw what different changes had happened. And so you got this sort of idea of an arc of education in which you've got a series of classes and each of those classes and each of those phases of education really are focused inwards, and they're not necessarily looking at the trajectory of what will happen beyond that institution and beyond education. The parents actually sit quite differently because they actually see what happens year on year.

And so they then start having to think about actually what happens post education, what happens when they get to the next phase. So the big transition for children in the UK is between year six, when they're about sort of 10, 11, and then year seven, where they are 11, 12, and they go from primary school, which is the first one, to secondary school, which is sort of where they move on and they go on and do their exams. And yet when you actually look at the whole structure of education, there's actually phases within that and actually each of those phases then generates gaps, and that's where some of these problems with the children were coming. So it was actually the gaps in between years and the gaps between segments that were actually quite important. And you saw there was variability year on year. I think if you look at, when we think about one of the things that came across the whole of this study, this was a secondary analysis about visibility. And across the original data, the parents had kept repeatedly referring to the difficulty of securing a diagnosis, and when they got a diagnosis, whether the schools

acknowledged it. And, you know, there was an awful lot around the issue of diagnosis.

So this secondary analysis just looked at that diagnosis side and looked at what purpose it served, how it got used and what its value was. And in terms of visibility, the diagnosis wasn't just a label, it was a capacity to make the child visible for all of their features. But it also served, interestingly enough, in the data, you see teachers saying, well, I had a child who was diagnosed and then I recognized that child's features also in some other children. And so I then sort of actioned that. So there's a value in terms of not the label per se, but the capacity to recognize a profile that has real merit beyond just a child having an identification, if you get my drift. So actually in the paper there's a set of 40 themes or sub features that go on to actually be kind of reduced down to the seeing, being seen and being able to see. And also one called the Boundaries of Diagnosis. And they're all different features that came through in terms of whether parents had successful or unsuccessful passages through the school.

And when you look at the 40 features, what you can see is that some of those are grouped together to make an effective transition through the school system. Some of them worked in opposition and some of them worked sort of together, but in a very negative way. And I think that checklist is actually quite a useful one for both teachers and parents and policymakers about what are the features for any given institution, and how does it set itself up? And that's particularly true where you had, say, schools where they'd followed the party line that dyslexia wasn't a thing. And so then they weren't acknowledging it and they were following the line that you only had one intervention that you needed to do, which was phonics. And sometimes, you know, those kinds of settings were very difficult for parents to navigate, where you had settings where people were highly informed and educated. There's a lovely account in one of them of a primary school and all the teachers were quite well educated. They'd all sort of got post graduate qualifications.

So their knowledge was very well refined. They were able to challenge the assumptions. They were able to develop programs that brought parents into the school and built connections. And so those kinds of things like school policy, gaps in knowledge, variability of staff performance and stuff, these are all in the framework that allows us to actually sort of describe dyslexia in terms of those three categories.

Dr. Monica McHale-Small:

Okay, so Julia, you're one of those researchers in the field of dyslexia. So what was it that you saw in Angela's work that you said, yeah, this is the direction that we need to go.

Dr. Julia Carroll:

Yeah, it's a really interesting question. Angela had a slightly rocky ride through her PhD. So she started her PhD with another supervisor, Professor Claire Wood, who then left the university before Angela had completed her PhD, and so I joined Angela's team after she'd already started. But when I was first introduced to Angela and her idea and her work, it was quite a step change for me. So I come very much from that kind of cognitive processing background. And I

think I may have asked her to explain why she thought parents would be useful to look at at all.

Dr. Angela Thompson:

I'm laughing at that.

Dr. Julia Carroll:

So it's been a really interesting journey for me because I think it has made me think about how important it is to have those different experiences recorded, and how important it is to think about a child's journey through education, as Angela's been talking about. And maybe from having my own children and watching them go through the education system as well. I think that has become more and more clear to me that teachers have a very segmented view of what goes on in a child's life. They don't, just as a nature of the system, have so much knowledge about the child's early years or background and so on. And so I think parents do provide really useful input. And I think Angela's argument about trying to integrate the emotional experiences and the more scientific approaches is something that we really need to work on. So Angela has very much converted me to her way of thinking.

Dr. Angela Thompson:

I'm really laughing because that very first performance review panel when we're doing our PhD., Julia was actually the external. She wasn't on the team at that point.

Dr. Julia Carroll:

It is my job as an external to ask difficult questions.

Dr. Angela Thompson:

But yes, it was very funny. And I think the other value is that if you have a lot of passion in an area, you know, Julia is absolutely magnificent at asking those questions, magnificent at challenging. And so my whole thinking got refined as it went on, which was a very happy sort of partnership that happened from that. So I think the actual paper generated from conversation with Julia, because she felt very strongly that the issue of diagnosis was really needed a proper unpacking. And we realized that I have the data to do that. And so that's really how this second set of analysis came out, you know, because the whole issue of diagnosis wasn't in the thesis because the simply just wasn't the space and it wasn't the focus.

But we did have the data for it. So we did this kind of analysis afterwards.

Dr. Monica McHale-Small:

And one of the things that really struck me about that and how you spoke about the importance of diagnosis, is that we're struggling with that same thing here in the United States. Way back now, going on 10 years, the federal Office of Special Education and Rehabilitative Services issued a guidance letter to all the school districts in the United States telling them that yes, you can use the term dyslexia and dysgraphia and dyscalculia. But here we are in 2025, and I'm still encountering school officials and teachers and others who are saying no, we don't use that

diagnosis or no, we don't need that diagnosis. We look at what the kid needs and we give them what they need. The diagnosis is superfluous. So I don't know if you have any additional thoughts to you?

Dr. Julia Carroll:

We have a very similar situation in the UK and I find it quite mind boggling really. I mean can you imagine a kind of parallel in the medical field of people being told they're not allowed to diagnose depression, that we just treat people as if they have depression. It just seems bizarre to me. But we have a very similar situation. So this is part of the motivation behind the Delphi definition work that I've been working on, that I talked about with you before, Monica, and also this paper. In this paper we really wanted to look at what is the benefit of having a diagnosis beyond that kind of approach of treating someone as if they're dyslexic. And so we have an example in the paper of a child whose school said there's no need for a diagnosis, we'll treat them as if they're dyslexic. And what tends to happen is that gets forgotten, or results in quite partial support and very patchy support over time. And also I think overlooks the importance of having a dyslexic identity. Is having that as part of your kind of understanding of yourself, which I think is really valuable as well.

Dr. Angela Thompson:

Yeah, I mean the one that Julia's talking about is the mum had pushed a lot for getting a diagnosis, and they had resisted as they said we treat him as though he's dyslexic. And then he goes up to Senior School Year 7 and he can't copy off the board, he can't put his homework down, he can't respond, because what had happened in the classroom is that they'd put accommodations in place, but not remediation. And so people think that when they're putting accommodations in place, they're doing the right thing by the children in that moment in time for them to access education. That is important. But if you don't put the remediation in, the accommodations are actually more disabling because simply you're covering over a problem. And then when they have to demonstrate their functionality, it's not in there. So I'm part of a sort of a group that's UK parents. I just kind of post occasionally with answers and stuff for those who have dyslexia, and the same stories are still happening. In one case, a parent was describing how the school had put it in place, so computers and stuff.

And then the senior school says, oh, we don't have any of that in the classroom. And how are you going to manage this then? So I think it's about recognizing that simply treating somebody as though they have...Because unless you've actually got the highly developed skills to be able to analyze what you're seeing, all you're putting in is generic, and sometimes not even scientifically accurate generic responses. And actually you're not accounting for what they're going to have to do in the future, which is where this inclusion idea of going across the span of education comes from.

Dr. Monica McHale-Small:

What were some of the things that jumped out? What were some of the areas where parents and teachers seemed aligned in their perceptions, and where were they most far apart?

Dr. Angela Thompson:

I'll kick off and you can join in Julia, if you want. They broadly were aligned in that children needed literacy skills. They both agreed literacy skills were important, and then after that it depended upon how well that relationship between the school and what they were doing linked with the parents. So if a school had a singular approach to dealing with, you know, we're going to do phonics this way and we're going to do it this way and this way and you know, parents are coming home saying actually little Johnny can't do this. He's stumbling after two words, he's getting distressed. And then depending on whether they sort of took that on board as being actually we may have to do something different, or you just need to work harder, depended on how far apart they went. So one of the things was actually to what extent, when they started on a trajectory of improving literacy, were the school able to take onboard the parent's knowledge, and how the parents were going to be able to try and support them. And one of the difficulties that they face is that if a school experience is fairly tiring, to the point of being toxic for a child, coming home and trying to do more schoolwork on the area of difficulty actually is really quite counterproductive.

And the importance of parents, you see in the data the importance of parents talking about the positive things that the children have, you know, supporting them in activities, sports activities, or creative activities, or things along those lines. So there was a difference then about how do you actually manage the school time. So I think they can agree that there's a literacy difficulty after that point. It's the degree to which they were able to communicate effectively and take on board each other's perspectives.

Dr. Julia Carroll:

Yeah, I think one of the really interesting differences that Angela found was about people's understanding or explanation of inclusion. So with parents, quite often when you ask them of an example of inclusion, they would think of an example where their child was given an opportunity to shine, or that they had a strength, or they had a positive. Whereas with teachers it was very much more about focusing on access to the curriculum and keeping up with the work and so on. So they had quite different views about what inclusive education might mean, I think. And that's something that we didn't explore too much in this paper, but it's something I think we would like to look at in the future.

Dr. Angela Thompson:

Yeah, I think the thing that you always have to remember when you're doing this research is that you're accessing the people who are willing to engage. There is a whole group of parents and pupils who are just not represented in the data that are difficult to access. But even within this paper, I did try and make sure I had people who weren't necessarily typically going to be included in papers. So I did try and get quite a broad array of people and I did try and get quite a range of socioeconomic experiences. But there is a need to try and get an understanding of what is that experience for education like for the child and also to the point, as they go through this whole education journey, how do their aspirations change? So there's a really sad bit in

there. I'm trying to remember if it's actually included in the paper. I think it is. And it's a parent describing how her child wanted to go off and be an architect and to go in to do sort of quite high work or work in the military, or something like that. So those kinds of aspirations. And then she's like, well, he got to 13 and he's only actually got a reading age of 8. I've just discovered this. And that actually he isn't going to get the qualifications because nothing's changed, and it's not going to change in time. And she's then saying, well, maybe he can do something with his hands. And so you sort of see these aspirations that could have been fulfilled, and you see that being completely squashed. And if you're interviewing it's quite hard to see that, and actually for the parents to articulate it as well.

Dr. Monica McHale-Small:

Yeah, I see that in my advocacy work. And just way too often children who could have gotten some help early on, and now they're entering high school and they're reading at a second grade, third grade level, and there's so little time left. Right? And, yeah, it's tragic. And it goes along with what you were talking about with inclusion, there was a sentence that really struck me because I was thinking about one little girl that I recently worked with.

And let's see, the sentence was, parents also saw dyslexia as a barrier to inclusion in mainstream education. And then we go on to talk about, I think it was another researcher that spoke about how their children were positioned at the lowest rung of being placed in the classroom, but without needs being met.

Dr. Angela Thompson:

That was our work. That was what we saw. So I think one of the really salient findings is that when people think of dyslexia, and this does go along with the definition. You're thinking about differences and deficits. What is interesting was that parents weren't really focusing on those, if you like, cognitive domain issues.

What they saw and how they got triggered in terms of dyslexia was their child was distressed. So that was the thing that kind of alerted them. They saw a child that was distressed or struggling. And so it was the lack of inclusion that was really the hallmark of dyslexia for the parents. And if you go right back in history, and you look at those very first cases they're presenting to a doctor, the fact is that the child is different and is not included. So this has always been part of the dyslexia story that it's a lack of inclusion. And then if you think about, how do we work out inclusion? I always have difficulty saying this name...Göransson and Nilholm, they kind of came up with these four hierarchies. So the bottom one was the child was just in the classroom. The next, the child's needs were being met. The third one was that all children's needs were met. And then the fourth and top one was that there was a community. When you started listening to the children's parents' accounts of their children, it was just a case of their child's needs not being met, or they were not consistently met. So sometimes they were met and sometimes they weren't. Sometimes year on year it was different.

And so it was just, you know, it was this sort of sense of the child not fitting in and actually not

the space or maneuver or capacity to think differently about how you might actually do a piece of work. Because if you've got somebody who doesn't fit in, it's easier to deliver for the mass and then say, well, I'll try and catch up on this one. If you actually try and make the whole thing work, you have to think quite differently about it. So I think that's some of the issue is that any child with dyslexia, or particularly one that's been picked up in the classroom, is always going to be in a minority. And so there's a lot of minorities across the classes, across a district or an area, but on their own they're not a big part. And it's the fact that the majority get the speed of the majority, the way the majority can work actually means that those needs just are not met.

Dr. Monica McHale-Small:

Maybe. I mean, we could probably talk all day about this because I think we have a lot of shared experiences around this issue. But from the work that you've done, what are some of the recommendations that you were able to draw from this work?

Dr. Angela Thompson:

So I think the first thing I would say that is important for any child is that the parents need knowledge. They need to get themselves educated, because the parent is going to be that child's voice in a way that is quite significant. Just sort of digressing at the side, I put one of these early interviews through one of these cloud systems where you make a cloud of words. And I was sort of sitting there at 2 o'clock in the morning looking at this, and it just had 'think' in absolutely huge letters in the center, you know, so this was the dominant word that parents were having to use when they were thinking about a child. They had to think all the time. And I thought, no wonder all of these mothers, because it's predominantly mothers, are so exhausted, because they're having to think not only for themselves, but they're having to think through the child's eyes. They're having to think about how to manage it. And so getting yourself educated is power. You know, it's the old Foucault thing.

Knowledge is power. And so you need to kind of have that knowledge to get yourself there. And the same is also true of teachers. So your first baseline is getting educated, and then the second is really trusting what you see in front of you and trusting and gathering the evidence so that you've got something to take back and communicate when you're dealing with teachers. If you've got a school that really, really isn't meeting your child's needs, you need to seriously think about, can you shift them? Can you do something different? Can you do something that is going to make sure that you build resilience and support? So if they're having a really toxic time in school. It's really important that they are doing a lot of other stuff to support their mental health outside. My two were actually quite good at maths and I never did lessons for literacy.

I did maths lessons because that's what they were good at, so they could feel confident in that area when they were in the class. We did all kinds of, the scouts, the art classes, the swimming, the drama. We did loads of creative stuff. We went for walks, did lots of talking, had audiobooks, did lots of reading. So we did lots of things that were positive, that were going to support language development, support confidence. You know, the school time will pass. It's how the child emerges from it that's important. And so it's about protecting them and then trying to make

sure that they've got the best access to learning, to finding the best way of learning for them. Do you want to kick in, Julia?

Dr. Julia Carroll:

I think you've covered things really well. I think the key is, as Angela touched on, is knowledge and willingness to learn in both cases. So knowledge for the parents, knowledge for the teachers, and willingness to communicate and learn from each other, and acknowledging that both have valuable viewpoints and will have information that the other doesn't have is really crucial.

Dr. Angela Thompson:

I think parents will sometimes give descriptions to school staff. You know, I had it in my research. They'll give descriptions and they'll give explanations, and they may not fit with the exact sort of knowledge that we have, but taking that description on board is really useful. So parents may look for attributions of why they have difficulty, but actually understanding what is being described is really very useful. In terms of that, in the actual paper are those 40 categories that I mentioned earlier and actually looking and seeing, for any situation for your child, which of those categories actually work for your child and which ones are working against? You know, if you've got variability of staff, have you got good staff that day? Well, okay, what are they doing that is helpful that you can then make sure you transfer that knowledge across to the next year? So there was a lovely account in the research of how a parent literally went year to year and described for each new teacher what that child needed. So she was making sure that knowledge between years got transferred. Because that's often one of the big gaps is that a teacher gets knowledge on a child, but the next one doesn't have it.

And there isn't a transfer system. So that costs nothing, but it's actually extremely useful. So teachers and parents getting together at the beginning of the school year and teachers saying, tell me about your child. What do they learn? And the parent finding, okay, how is it you need to work and what are the things I can do to support you? So I think having that. So those 40 categories are actually quite useful on both sides, I think.

Dr. Monica McHale-Small:

Okay, I'll end with a curveball, one that we didn't talk about. Maybe Julia can kick it off or maybe not. If after writing this paper, after considering this research and your other work, if you had a meeting with an influential policymaker and you only had a few minutes to speak with them, what would be the things that you would want to make sure to share?

Dr. Angela Thompson:

Lovely silence. Then I would probably say, if I only had a few minutes. Listen, you've got a school system which is unintentionally generating disability, and it's doing things that can be very quickly changed, that don't actually cost much money, but which actually would make a big difference for children, and that's a transfer of information between years. It's about looking at how effective your communication policies are with parents. It's about making sure your staff

have got somebody who is knowledgeable to go and ask. And it's about understanding that inclusion isn't a child sitting in a classroom and just because they're a minority, they still count.

Dr. Julia Carroll:

A few things...as I said, it's really amazing that schools can decide, or school boards and education authorities in the UK can decide not to recognise dyslexia. I think that we do need some top down arguments that dyslexia is found universally in every country in the world, and dismissing the existence of dyslexia is counterproductive. It does not get rid of the issues, it causes more problems later on in life. I think the central issues I would be trying to focus on would be teacher education, teacher knowledge, and encouraging greater understanding within the teacher profession of how common dyslexia is and what the key characteristics are.

Dr. Monica McHale-Small:

A perfect way to end it. So thank you, both of you, for your time and for the work that you're doing on behalf of children with dyslexia.

Dr. Angela Thompson:

Thank you.

Dr. Julia Carroll:

Happy to share the knowledge with you, Monica.

Lauren Clouser:

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