



Defining Dyslexia in the UK: A Delphi Study

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. Hi, everyone. Welcome to the LDA podcast. We're here today with Dr. Julia Carroll, who is a professor of psychology and education at the University of Birmingham. Her research focuses on improving literacy outcomes for children and young people, and she is the lead researcher on a recent study entitled: Towards the Consensus on Dyslexia, Findings from a Delphi Study. LDA's education director, Dr. Monica McHale-Small and Dr. Carroll will be discussing this research and its impactful findings.

Monica McHale-Small:

Okay. Thank you, Lauren. Professor Carroll, I am so thrilled to be speaking with you today. Someone had sent me, and I'm not even sure who it was, had sent me a preprint of your article back in September. And I was so excited to see that because as you now know, LDA was working on SLD evaluator principles and standards. And reading through your work, that preprint, and thinking about the work we've done on our standards, the process was a bit different. But I do think that our aims in doing the work, our work, was very similar in that we're trying to improve outcomes for individuals with dyslexia, and in LDA's case with other specific learning disabilities as well. So, I'm wondering if you can begin by telling us a little bit about your research interest pertaining to dyslexia and why you chose to be part of this project.

Was this your idea, this research project, or how did it come about?

Julia Carroll:

Okay. Thank you. So I've worked in the field of dyslexia since I did my PhD, which was over twenty years ago now. I'm particularly interested in understanding the causes of dyslexia and also how dyslexia overlaps with other specific learning disabilities and other difficulties. So a lot of my research has been looking at the similarities and differences between different learning disabilities. But this project particularly came out of, I wouldn't say it was my idea. I would say it came out of discussions with collaborators. So, in the year 2020, I wrote a review for the UK government about the current state of science and understanding about specific learning disabilities and dyslexia in particular.

And I highlighted there that there were differences in understanding in schools and in universities and colleges, and in the workplace, and differences in the process of how people were assessed and what was expected for the assessment in those different places. I then

became aware of the SLD assessment standards committee, which sounds like they have some overlap with the LDA or that kind of parallel with the LDA. They provide guidance on assessments for specific learning difficulties or disabilities. In the UK, they were carrying out a review on guidance for assessments for dyslexia. And at the same time, the British Psychological Society were also carrying out a review on guidance for working with dyslexics. And it seemed like these two things were going on in parallel. There wasn't that much overlap between them. So in the UK, dyslexia can be diagnosed by a psychologist or by a specialist teacher, but it's deemed the guidance for those two groups wasn't necessarily the same.

And so I was part of the group that suggested that we tried to come up with consensus across, across the teachers, specialist teachers, and psychologists to try and agree to a way forward that we could have a consensus definition that could be used by people with different ages age groups, different backgrounds, and so on. So I was talking to my former PhD supervisor, Maggie Snowling, about this, who'd she'd taken part in a Delphi study looking at developmental language disorder led by Dorothy Bishop a few years ago. And she highlighted that a Delphi study would be a great way to try and build that consensus. So that's what we decided to do here.

Monica McHale-Small:

Okay. And it's interesting too because it seems like there were similar parallel work going on in the United States while LDA was writing their evaluation standards. Like you mentioned, it was happening in the UK. Also, the International Dyslexia Association recently published some papers reexamining the definition of dyslexia.

Julia Carroll:

Yeah. So we didn't know that was happening at the time, but it does seem like everyone kind of was coming to the idea that it's time to reestablish what the core principles are, I think.

Monica McHale-Small:

Do you have any thoughts on why that might be happening right now or how that relates to the importance of this work at this time?

Julia Carroll:

No. I think I can talk about why it seemed to be happening in the UK. So I think, also, one of the factors that we were concerned about in the UK is that there still wasn't consistent recognition of dyslexia. So there are some local authority areas which kind of manage groups of schools that encouraged their schools not to seek diagnosis for dyslexia saying that we know how to help struggling readers, and we don't need to have a diagnosis. So, I think in part, we wanted to examine that idea and try and show why we think it's useful to have the option for diagnosis, because it felt like we were almost taking a step backwards. So we'd made some really good progress in recognition and support for individuals with specific learning difficulties. And then it felt like things, I think when budgets grew tighter, there was there's just less time, and people were trying to maybe prioritize that it seemed like there were children with dyslexia or specific

learning difficulties seem to be getting left out of the equation, and we were worried about that, I think. I don't know if that's similar to what you felt in the US.

Monica McHale-Small:

It's amazingly similar. We think, yeah, every country has its own issues, its own, problems that it's dealing with. But in the United States, it back in 2015, the Office of Special Education Programming in The United States put out a letter, a guidance letter to school districts saying that dyslexia is a legitimate classification diagnosis under specific learning disability, and schools can and should be diagnosing or classifying students with that disability and and appropriately intervening. But here it is now 2025, and I still come across routinely schools that are saying, no. We don't use that word in our schools. And I've never figured out exactly why, but there's speculation that, yes, maybe it's related to funding. But I do think it's also related to something else that you said that there's this belief that when we know how to teach reading so if we just teach reading the right way to everyone, we take care of the kids with dyslexia, and we don't need to worry about a diagnosis.

Julia Carroll:

Yeah. Yeah. And I think we're seeing some of the consequences of that, and I'm sure you've seen some of the consequences of children who've had the extra help with reading maybe, but haven't had the recognition that they have dyslexia. And then, when the reading class demands change, you'll get more complex or as they get older and organizational factors come in, then they start really struggling, and they don't have that kind of identity and self knowledge that they might have had if they'd had a diagnosis.

Monica McHale-Small:

Yeah. I absolutely agree. I do think the methodology that you used in your research was very interesting, how you got to that consensus. And you explained it very well in your paper, but, of course, probably not everyone listening today is going to go and read that paper. But maybe you could give us a little overview of how that research was conducted.

Julia Carroll:

Yeah. So the Delphi approach is an approach used to try and gain consensus on a contentious issue where it seems like there's disagreements. So, we start with a set of statements, and we ask an expert panel to respond, to review whether those statements say whether they agree or whether they have any comments about the statements. Then we take those ratings and the comments about the statements, and we share them anonymously with all the other members of that expert panel so people can see how much they align with other people, and they can read the comments and see if they agree or disagree with them. We also use those ratings in the comments to decide whether to accept certain statements or not. So in this case, if more than 80% of the panelists agreed with the statement, then we said that that was accepted. If we had lower than 80% agreement, well, we looked at the comments in any case just to see what people were saying. Sometimes people suggested minor changes to the wording, but still agreed.

So with the statements that had lower levels of agreement, we looked at the comments people had made about them to look at whether we could improve the statements to make them statements that people would be happier to to agree with. And then we sent out another batch of those revised statements, and we had 55 statements in the first round, 22 in the second round, and, again, asked people to rate them and put comments on them. And, again, we were able to accept some of those revised statements. And so at the end of the process we had 42 statements that had higher than 80% agreement, and we could use those as statements that we could argue had a clear consensus around those and use those as the basis for developing a definition and moving forward with that definition.

Monica McHale-Small:

I did notice that in your paper that you included individuals with dyslexia in your stakeholders group. Can you tell us a little bit about why your group thought that was important?

Julia Carroll:

Well, I think it's important for multiple reasons, but, really, because we were looking for consensus. We wanted to have consensus from people who were going to use the term and people who identified with the term. So we didn't want to have something in the consensus definition that didn't align with what people wanted to say about dyslexia, I guess. So we wanted to have individuals with dyslexia in there to make sure that we had their voice and we had their opinion, and we weren't saying statements that they would find, didn't fit with their identity maybe. So some of the wording in particular, so things about whether to talk about, co occurring disorders or comorbid disorders. Certainly, individuals with dyslexia have said they prefer the term co-occurring. So, that's the term that we've gone with because we want to be as inclusive as possible while still being clear with the language, I think.

Monica McHale-Small:

Great. Alright. I think it's really important. There's a saying in the disability community in the United States. I don't know if it applies in the UK, but people advocating for disability rights use 'nothing about us without us.' So I think it's very important to get the voice of the individuals who are most impacted because they live with the condition.

Julia Carroll:

Yeah. Absolutely. Yeah.

Monica McHale-Small:

So a lot of things jumped out at me, and I don't know if I necessarily have questions or more comments. But before I go on to those, I was wondering what were the findings that you found to be most salient that really resonated with you?

Julia Carroll:

I think in some ways, I was surprised at how much consensus there was because maybe the

dyslexia community has a reputation of having disagreements and debates within the community. But, actually, there's a lot that we agree on that we found consensus about, which is great. So, and I think so some of the things were around kind of basic tenants. So, all children with literacy difficulties should receive appropriate support. I think that's fairly straightforward, but it is something that everyone agreed with that we shouldn't be deciding on what support is allocated to people purely on the terms of diagnosis. We should be thinking about diagnosis as something that we look at for individuals who haven't responded well to standard additional literacy support in the classroom, particularly. I think another area that I was surprised and pleased to see so much agreement about was around multiple deficits. So previous definitions of dyslexia have really focused on phonological deficits as being the core underlying difficulty in dyslexia.

But I know that certainly assessors and individuals working with dyslexia talk about a range of different difficulties, and so that's becoming more prominent in the research literature as well. So I think there's growing evidence that focusing only on phonological deficits is not the right way to think about dyslexia, and we got consensus around that with the panel. So, yeah, I was really pleased that we got that.

Monica McHale-Small:

Alright. So yes. And some of what you're mentioning is what jumped out at me. But before I go to that, you said something about, you know, the consensus that we have to provide the supports to everyone. And I think that relates to one of the things that we discussed in our standards paper at LDA was, there's a difference between having a disability, meeting an eligibility requirement for services in a particular state or school district in the United States and then having a need. And that if we're gonna best serve individuals, we have to look at all of those things. What we see as a tendency in the United States and schools that if a child doesn't meet the eligibility criteria, for receiving services, then we don't even think about whether or not they still have a disability, because not everyone who has a disability is going to meet that threshold for special education services, but it doesn't mean they're not going to need accommodations or other services provided to them. And I think that your work kind of led to similar sentiments.

Julia Carroll:

Yeah. Yeah. Absolutely. I think so.

Monica McHale-Small:

I appreciate you talking about the different possible cognitive processing impairments and that it's not just phonological. And that was something that we really emphasized in our LDA standards is that, you know, there's individuals with, SLDs, specific learning disabilities. They they struggle with reading and writing, and math, but they also have these cognitive processing difficulties, that it's more than just needing the good instruction that all children need and deserve, but they often, because of these processing difficulties, also have other needs that, like you mentioned, as they get older, organization. But we find that, you know, they need

accommodations. They continue to struggle even if they've gotten more accurate with their reading. So that was just a comment that I had.

Julia Carroll:

Yeah. Absolutely. So I think the first statement that we have in the definition, highlights that the set series is about a set of processing difficulties that lead to reading and spelling difficulties. So there are some definitions that just rely on the reading and spelling difficulties on their own. But, that leads to all sorts of problems, and it does lead to individuals maybe not having difficulties supported appropriately if they have those processing difficulties that can cause difficulties in other areas. So we've tried to emphasize the processing difficulties, I think, very similarly to how you have in your document. Because individuals can learn to overcome reading difficulties in certain situations, but it doesn't mean that the underlying problem is fixed.

There are still needs that need to be supported.

Monica McHale-Small:

Yeah. I also really appreciate your statement. Well, your statement six had to do with orthographic processing, and there was a suggestion that further research is needed. In speaking with some folks here in the United States who are researchers, some have told me that, you know, we know what we need to know about dyslexia and learning disabilities, and we don't need a whole lot more research. And I'm not sure that...no, I know I am sure I don't agree with that, and it sounds like you may not either.

Julia Carroll:

No. I think I actually had someone come to me as a PhD student several years ago who said, if we know all this about how to teach reading and spelling effectively, why do we still have these children who were really struggling in school? And I think that's the key question. I I don't think we can say that we know how to fix this until we can show that we regularly fix it. And, actually, I don't think that's true in classrooms. I think we still have young people who are underachieving quite systematically in the UK because of dyslexia and not having, well, even when they've had additional reading support, they're still having difficulties. And I think trying to understand what those difficulties are is really important. One thing that I say quite often is that by definition, dyslexics are those children or individuals who have not had a good response to standard classroom teaching. So what works for most children and young people hasn't worked for them.

We don't necessarily know the reasons why that is, and it's likely to vary across dyslexics. But I think there's a lot still to understand about why some individuals struggle so much with this.

Monica McHale-Small:

Right. And I find right now, LDA is in the midst of doing some survey based research on the experience of adults with dyslexia and other learning disabilities. And it's interesting to me because often when they describe their struggles, reading, writing, and math are not the first things they talk about. They talk about things in life that they continue to struggle with. So I think

there is a lot we need to uncover about those cognitive processes and how they're really impacting someone across the different domains of life.

Julia Carroll:

Yeah. And I find it so interesting how those cognitive processes interact with the experiences a person has and their personality in the way they react to situations. It can be very individual, the experiences that someone can have. And understanding how that comes from the basic processing difficulties, I think, is still something that we don't have a clear picture on.

Monica McHale-Small:

So a couple other things that really stood out to me is that, the focus on there was a high level consensus on reading fluency and spelling as really key indicators. And I find that interesting for several reasons. It took a while. It took until 2004 reauthorization for IDEA, the federal law in The United States, to recognize reading fluency as an area where a student could have an SLD because it needs to be specified if it's in basic reading, reading comprehension, reading fluency, or some combination. And now math fluency is not included. We get problem solving and application. And with writing, it's written expression, but you can't qualify just on spelling. So I think that's interesting because also my own adult children, two of them had dyslexia diagnosed when they were younger, and spelling is really where they still get hung up.

They're very slow readers, like their mom, but spelling continues to be a real challenge. So I thought that was interesting.

Julia Carroll:

Yeah. Yeah. Absolutely. Spelling always seems to be the overlooked element, but it is actually one of the most persistent difficulties. And certainly with adults, what you see in the research is that spelling is a difficulty that lasts much longer than the basic reading factors. So we wanted with this definition, one of the issues that some people raised with the previous definition that was widely used in the UK was that it was very focused on children and very focused on English-speaking populations. So I think talking about reading fluency and spelling is really important when you are also thinking about adults and when you're thinking about dyslexia in other languages, because often you see in particularly in regular orthographies, more straightforward orthographies like Spanish, where children can work out how to pronounce a word through phonics, but they can't necessarily produce it fluently.

And so fluency is a really powerful marker for underlying difficulties, I think, is our feeling. But, again, I think we need more research around spelling. And so in the preprint, one of the minor changes from the preprint to the final version is that we talked about spelling fluency in the preprint. But actually, when we went to look at the research evidence, I couldn't find any research evidence about spelling fluency in dyslexia, at all. So it's not mentioned, but I think that's a real area for future research because we know that dyslexic individuals have difficulties with recalling spellings quickly and efficiently. It's just we don't have it kind of published in research evidence, really.

Monica McHale-Small:

Yeah. Yeah. I often see adults with dyslexia, when they're looking at their own writing, they have to, oh, that doesn't look right. But it's not until they have it on the paper that they realize it doesn't seem right, and they have to go back.

Julia Carroll:

Yeah. Well, they know it doesn't look right, but they're not sure what's wrong with it.

Monica McHale-Small:

Yes. Or sometimes it's spelled right, but it still doesn't look right, and they have to go and check and make sure they have it right. So let's see. So it is interesting to me that statement 41 in your paper pertains to intellectual ability. So it seems like your group feels that there is some role for cognitive assessment when evaluating and planning intervention for individuals with dyslexia. Would you agree?

Julia Carroll:

Yes. So this was I think this was probably the thorniest issue that we had, that that was hardest to get agreement on. And, actually, when I looked at the recent publications around the IDA definition, it seemed like intellectual abilities and the role of testing for intellectual abilities in dyslexia is a thorny issue in the US as well. So, we actually had, after the panel, we got the comments from the panel. We had a face to face discussion, and one of the key elements there that we focused on was intellectual abilities. So the previous widely used definition in the UK had had a statement in it that said dyslexia occurs at all levels of intellectual ability, which I think might have given the impression that there was no point in testing IQ at all, that it should just be about testing reading. And some of the feedback we got from the panelists was that they wanted more discussion or recognition of the role of intellectual abilities, including in testing adults as well, where you've got less so with when you're testing children, you can look at their reading age, look at whether they're reading at a typical level for their age. But with adults, it's much more variable what you would expect from reading, I guess.

So, yeah, I think we have come down on saying that we think that testing IQ should be not purely a numerical factor. It's not purely looking at a strict discrepancy definition where you're looking at the difference between two numbers, but you're using it as part of a holistic assessment to try and get a picture of an individual's strengths and weaknesses to understand the profile. We've tried to highlight that children with what we would call generalized learning difficulties, like I think you'd call intellectual disabilities. Dyslexia may not be the most appropriate label, but it's not necessarily the case that you should never use it is what we've come down on in the end.

Monica McHale-Small:

And that prior statement that you made about really understanding the profile of the learner and their strengths and their weaknesses sounds like it could have come right from our LDA paper.

Julia Carroll:

If I'd seen the LDA paper before we started the research, I think we probably would have used it as a basis for some of the statements because some of the things that you've put in there are very much along the lines of what we were looking for.

Monica McHale-Small:

Thanks, that makes me very excited, and it all feels good when people, who are highly respected like you and your team come up with some of the same thoughts and ideas as we did. So we're thrilled. It was very validating to us to read your paper. So what are your hopes? How do you think your paper will change practice and policy in the UK, and maybe in other places?

Julia Carroll:

Well, our main hope is consensus. So I'm hoping that we can move towards a system where we have a pathway for individuals with literacy difficulties or dyslexia where there's a recognized procedure that they go through, whether that's looking at a response to intervention framework, which I think is likely to play a part in it, and then having a clear point where a full assessment should be done. So at the moment, we feel like there is just not enough consistency across the system, and that's really difficult for parents of individuals with dyslexia, because they don't know what they should be doing, which way to turn. So we're really hoping that we can create a system where we have consistency, where a parent or an individual can come in and see what the steps and the process would be rather than kind of fighting for recognition at every stage. So, yeah, that's what we're hoping for in the UK. And I think we feel like there's been a recent change of government. There's more focus on supporting individuals with special educational needs and I think some appetite for change.

So I'm hoping that it will lead to consistency and recognition. And I guess also, consensus and consistency across research and practice. So I think one of the things that I felt came out when we did the research was that academic researchers aren't necessarily listening to what assessors and teachers of dyslexic individuals are saying. They might be using slightly different definitions for dyslexia, which then makes it harder to translate across from theory to practice. So I think consensus both within the experience for dyslexic individuals and also between theory and practice.

Monica McHale-Small:

Yeah. That sounds wonderful. And I'm curious. So in the United States we have our federal law and guidelines, but every state kinda has a lot of leeway in interpreting them. So we have a real issue in the United States with eligibility criteria, changing one state to another. So you could be SLD in school in one state and not in another state. And in some places, that can even happen from one district within a state to another district. Is it like that in the UK, or is there more kind of central control of things?

Julia Carroll:

It is a bit like that in the UK, which I think is in some ways, I've it's quite surprising. Because generally, in the UK, or I should say in England. So we have different systems in England, Scotland, Wales, and Ireland as well. But generally, we have more top down, we have a history of more top down control in education, I think, than the US. So we have a national curriculum. We have national testing at various ages. We have comparisons between schools and so on. But in the area of special educational needs, there's much more freedom and variation in practice between different local authorities and also the extent to which the schools have to follow the local authorities' guidance.

So in some areas of education, it's very top down. For some reason, it doesn't seem to be so top down in terms of special educational needs, and that is something that I would like to see more official guidance on because I think it feeds into the difficulties. It makes it difficult for teachers to know what to advise parents to do, and it makes it difficult for parents to know what to do. And yeah, it just feeds into difficulties at every stage.

Monica McHale-Small:

Yeah. I understand. So I know that this first paper was focused mostly on the definition of dyslexia and the experience of individuals with dyslexia. Are subsequent papers planned?

Julia Carroll:

So we have another paper that's come out about good practice and assessment. So that one's much more directed towards assessors talking about how you can use the consensus statements to guide your assessment. And, again, I think that's very much in line with your guidance talking about the holistic assessment, thinking about and understanding why an individual might show a particular profile and so on. And I know that Dyslexia Journal has invited responses to these two papers. So, I don't know what responses we might get, but we'll see what responses there are. But, yeah, I think one of the best things about the project is that because we were working with the SLD assessment standards committee, they've taken that definition and they've used that as guidance for dyslexia assessments. So it's been implemented quite quickly. It's gone into practice, which is great.

Yeah. And I think for my own future research, I would like to focus on the experiences of individuals with specific learning disabilities. So we've done some work on their kind of social emotional experiences, but actually, what it feels like when individuals are reading and spelling is something that I think we don't have a very good picture on research wise at the moment.

Monica McHale-Small:

Well, I could talk to you all day long, but I appreciate the time that you've given us. And are there any other closing comments you'd like to make?

Julia Carroll:

I don't think so. It's been nice to talk to you and nice to look at your findings on your website and

so on. So, yeah, it's great. Thank you.

Monica McHale-Small:

Thank you so much.

Lauren Clouser:

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