

## UDL Research in 15 Minutes

With Dr. Lisa Jacobson

LOUI: Hi everyone. Welcome to UDL Research in 15 Minutes. During the following episode, I chat with Dr Lisa Jacobson about the effects childhood cancer has on learning. According to the American Childhood Cancer Association, over 300,000 children worldwide are diagnosed with cancer each year. Here in the US, about one in every 285 children are diagnosed. September is Childhood Cancer Awareness month, and I can think of no better way to move that awareness into action than to take what you learn during this podcast, apply it, and then share this podcast with others. Thank you. [Music interlude] Hello, and welcome to UDL Research in 15 Minutes where researchers share their findings about the implementation, impact, and their introspective investigations about UDL. I'm Loui Lord Nelson, UDL author and leader, and today I'm talking with Lisa Jacobson who works at the Kennedy Krieger Institute as the Director of Research, a licensed psychologist and pediatric neuro psychologist in the Department of Neuro Psychology and the Co-Director of the Center for Innovation and Leadership in Special Education. She's also an Associate Professor in Psychiatry and Behavioral Sciences at the Johns Hopkins University School of Medicine. Today, Lisa and I are going to talk about the research that she recorded in her article: "Beyond risk-based stratification: Impacts of processing speed and executive function on adaptive skills in adolescent and young adult cancer survivors". Hello Lisa, how are you?

LISA: I'm well, thank you very much.

LOUI: That's good! So, I made an assumption here, I can call you, Lisa? Is that alright?

LISA: Feel free!

LOUI: Okay. Thank you very much. I've known my other guests beforehand, so it's so lovely to meet you.

LISA: Likewise.

LOUI: Well, thank you. So, this is going to be a different article to hear about from the others for my listeners, because your research is not specifically about UDL, but listeners are going to really quickly understand this connection and why it's so important. But before we get started down that path, can you give us a little bit of background about how this relates to education and you relate to education?

LISA: Absolutely. So I actually started out as a school psychologist, several, several years ago, worked in Virginia and North Carolina, and then became really interested in sort of the, what I was beginning to learn about neuroscience and became a pediatric neuropsychologist, but I've kept my school psychologist, sort of practice and experiences sort of near and dear to my heart so that my focus is now on supporting children as they interface with medical treatment, and continuing to school or going back to school after their treatment or after they've started their treatment. So really thinking about how families and providers can support each other in navigating that process.

LOUI: Yeah, that's a big process. So can you connect your connection to UDL is, I think fairly recent. Can you talk about that connection?

LISA: Yeah, absolutely. So, I was actually introduced to UDL by Dr Lisa Carey, a colleague of mine here at Kennedy Krieger Institute and our Center for Innovation and Leadership in Special Ed, and as she introduced me to it. And I've read more about it, I realized how well the UDL framework and the specific guidelines really address the needs of the kinds of patients that we see in a neuro psych department. You know, seeing patients with learning, medical, and developmental needs, you know that come in for evaluation. And I think what's most important and what I really taken away is it helps us as outside clinicians who are not part of a school system, and many of whom don't have that school psychology background and having sat in millions of IEP meetings, a shared language with educators, that can really help us clarify strategies to

support individual patients in language that hopefully school teams will fully understand where we recognize that in the reports there will be medical language that probably is more difficult. So I've worked with my trainees and my colleagues to help incorporate UDL language into our recommendations.

LOUI: Nice. Oh, that's lovely. That's wonderful. So, as you kind of alluded to this read this article as part of a line of research, where you and your colleagues have focused on the learning needs of pediatric cancer survivors, and specifically how their executive functioning and adaptive skills are affected. So, this is really important research and a bit of a wake up, I think for educators who are working with students who are survivors of of cancer, but to give us a little bit of scaffolding, if you could help us understand the difference between executive functions and adaptive functional skills or function skills.

LISA: Yup! Adaptive function, adaptive skills, adaptive functioning. Exactly. I think that that's important because I think a lot of school teams in my experience at least, tend to think of adaptive functioning as something that we only think about for individuals that might have an intellectual disability. So, we assess adaptive skills in the context of an ID classification or diagnosis. And that's just not true. So adaptive functioning means general life skills, managing your daily self-care, getting your chores done paying your bills if you're an adult, behaving appropriately in social interactions and functioning, navigating across settings right school home community all of those places. It really just means everyday real-life function across all the domains that we find ourselves. So your personal hygiene, getting dressed, all the way to conversing with other people about current events. So doing that well. That all takes a degree of adaptive function. Executive function, or EF, I'm going to call it EF to be a little easier, refers to a specific set of cognitive skills that we use for goal directed purposeful activity and regulating our conduct. Again, it has, you know, there is an interface with adaptive skills, which is what we were investigating, but it's really about independent regulation of action and affect is how I think about it. So behavior and emotional reactions, and that spans the gamut from very simple kinds of things, all the way up to very complex kinds of behaviors. So, there's skills that support our reasoning and our thinking. But regardless of how

intelligent we might be, the same way that like a clutch in a stick shift engages and applies a car's motor, horsepower. So you can have the best, fanciest car, and the biggest motor, but if you can't drive a stick shift, you're not going anywhere, right?

LOUI: Right!

LISA: EF skills really set that stage. They help you engage and apply the skills that you have, the ability that you have. And so, it's in the face of something novel and new tasks, something that you've never done before, you have to stop and really think about, "How do I do this?" Whereas if you're driving to work on the same route that you've driven a million times, you probably get there and don't really remember all of the details. And so, we think about it as sort of top-down control of complicated or affectively engaging kinds of things. When you're really frustrated or you're dealing with a difficult colleague or a difficult student in your classroom and you really have to stop and think about, "Okay, this student is not trying to push my buttons. I need to inhibit my own emotional reactions plan my own behavior in order to support that child in being as functional and successful as possible." So, we use EF to get to successful adaptive functioning to figure out what to do in the new situation when we're on the wrong bus by accident and now what happens, right? Or to plan ahead for all the tasks we have to get done, and to manage our emotions, in the process.

LOUI: Nice. Oh, that's awesome. Thank you. Great, great, I love the analogies. I think the use of the clutch and then getting on the wrong bus or right bus and all that. Thank you.

LISA: Absolutely,

LOUI: So, in this article, you broke apart the adaptive skills and into adaptive behavioral, adaptive conceptual, adaptive social, and adaptive practical. So can you help us understand why those four areas were so important?

LISA: Absolutely. I think the distinction is a little theoretical, so when the individuals who developed adaptive scales, adaptive skill scales, sort of began to put those together, they really did think about sort of theoretically, what are the different domains in which people have to function? And so, when we think about, it's like component scales like a total achievement score might be broken down by reading, math and written language. So, you've got these different components, you kind of average them together and you get this total score. Conceptually, in that conceptual domain, we're talking about behaviors required for communicating with other people, managing and accomplishing tasks and applying your academic skills to other tasks. So not necessarily your academic achievement, but how well you can apply that to things like again, paying bills, or saving money. The practical domain is things we think about is more activities of daily living sort of the classic behaving at home, your personal hygiene, navigating your community without getting lost, those kinds of things. And then socially the social domain is things like interpersonal, those interpersonal conversations I was talking about acting with social responsibility, engaging in leisure activities, right? Picking game taking turns, you know, those kinds of things, some of that. But in this case with this article in particular what we wanted to show was that EF skills didn't just help us understand somebody conceptual, or the more academically related kinds of adaptive skills, they actually predicted social and practical everyday behavior as well.

LOUI: So, there's a really telling sentence in the discussion area that stated that I'm going to read it: "Overall metacognitive executive function was the most consistent and sizeable predictor of adaptive functioning across domains." So that link between EF and the adaptive functioning sounds really important as you just talked about a little earlier, and it probably has some direct implications for the classroom. So, can you talk about that relationship and why that's really important for us to think about in the classroom?

LISA: Absolutely. So, the label used in that article and on the measure metacognitive executive function really refers to again, how somebody can regulate their behavior in terms of getting started on tasks, holding information in mind that they might need to do it, like where you are the division problem, planning how you're going to accomplish your goal, goals, organize material, self-evaluate or self-monitor your progress towards

those goals, right? Those are the more cognitive aspects of EF. Relative to what I mentioned before, regulating emotions or regulating effect right it's kind of if you split those out, it's not as much of the inhibiting reactions, but it's really more about, sort of, those complex kinds of tasks. So our findings suggest that those EF skills in particular are really critical life skills for meeting daily expectations across settings, right?

Including home and classroom and for some individuals work. And so, if you don't have those or those aren't developing appropriately, nobody helps you, then, the lack of these skills can limit your day-to-day performance, even in the context of generally appropriate IQ. So, we controlled for IQ in the study, and so to go back to the analogy of the clutch, you need those skills to really apply your ability so you can be successful, even outside the classroom. But when we think about the classroom and supporting EF at school, I want to take a second if I can and highlight the concept of early developing versus later developing EF skills which I think is really important and the differences with that, with the UDL framework. And so, it's important for educators to recognize that it takes quite some time for children to develop executive function skills, some of us would argue that we know some young adults that haven't quite gotten there yet, right?

LOUI: And older, and older adults!

LISA: Yeah [laughter]. And older adults. Especially in the context of COVID but we're all stretched that. So we think about the foundational EFs as being early developing, so things like inhibition, working memory, shifting flexibly between tasks and events, more or less in that order. They develop more or less like that, you know starting early on in childhood and they form a groundwork or a foundation for the more complex and later developing EFs, things like planning and organizing and self-monitoring, you can see even self-regulation of emotion and affect because that's what's a really hard you have to be able to inhibit in order to be able to regulate your emotions. But if you think about the UDL guidelines, which ones are emphasized? It's the metacognitive, it's the much more complex ones. And so, what I mean is that the guidelines actually potentially over emphasize those more advanced EF skills and under emphasize the role of development, and the teacher's role in an educational context. So, teachers in an

elementary school, or even later, if you're thinking about students with disabilities, it takes them even longer to develop these skills. Those teachers as educators will need to scaffold early EF skills before you can even think about your student planning their assignment or monitoring their success, right? So, getting your students to a place where they can have those initial pieces of EF, those foundational skills, will help them with the later ones, and also as our article shows has sort of long-term, real-life implications.

LOUI: Yeah. So, another thing I was thinking about with this, we talk about variability via UDL and that, you know, all learners are variable but we also have some predictors. In the sense that we always know that we're going to have some students who don't read as well, or they struggle with math or they'll struggle, we just know we're going to have these different variabilities present we may not even know which student it is so we plan for that ahead. But what this article made me think about was if we know that there is a child who has experienced childhood cancer, then, this adds, it's another layer of variability, and that we need to be attentive and already preparing for these adaptive skills and then also the EFs, so that's what I was thinking and I would love to hear your thoughts on that, too.

LISA: Absolutely, I think we know that the treatments for childhood cancer tend to have impact on white matter in the brain, and that what matters is what supports us as being efficient and being able to integrate our brain networks fast, efficiently, and so if you can't do that, then the whole concept of executive function becomes much harder. Because there's no one part of your brain that does EF in isolation, right? It means you have to bring everything online fast, and often in the context of a situation that is challenging, right? Novel or challenging. And so, it's mixed, you know. It makes you need those EFs even more quickly, often in order to get yourself to handle the situation well. And so, these children are at risk for having more difficulty, and there's definitely variability even within that population, of course, given the kinds of treatment, and the age they were at the time. And so, I think cancer is a good model for that but we certainly see that across a variety of neurodevelopmental conditions or chronic medical

conditions like Spinal Bifida or cerebral palsy or, you know, all kinds of other somewhat lower incidence disabilities when you think about those specific named ones but broadly, children that have learning disabilities or ADHD are more likely to have difficulty with these scales as well.

LOUI: Yeah, it's just it's such an important part of our framework to get to know so deeply. But I think your comments about how we kind of need to scaffold our own work in how we're, as teachers, approaching it and then our, our depth of learning about executive functioning and understanding that we need to support the emergence of that. And possibly where we're kind of starting within the framework might be a little too advanced for, for some of our students. Yeah, thank you for that. Well, this has been wonderful. I know it's a snapshot, it's a tiny sliver of this entire article. So those who want to have access to it, I'll talk about that in the outro but thank you so much. This has been so wonderful and I think there are a lot of people that are going to listen and be like, "Whoa!" Their brains are going to be buzzing! So, thank you so much!

LISA: You're very welcome. Thank you for having me!

LOUI: You're welcome. So, for those of you listening to this podcast, you can find supplemental materials like a recorded video of this interview with closed captioning, and a transcript and my website, which is [www.theUDLApproach.com/podcasts](http://www.theUDLApproach.com/podcasts). The citation for the article we discussed as well as any other reference material can be found below the video representation of this podcast on my UDL Research in 15 Minutes YouTube channel. And finally, if you are a UDL researcher or know of UDL research you'd like to hear about, contact me through my website, [www.theUDLApproach.com](http://www.theUDLApproach.com). I'd love to hear from you. And thanks to everyone for your work in revolutionizing education through UDL and making it our goal to develop expert learners.