Transcript of The Reading Brain – Neuroscience and Implications for Assessments After Hemispherectomy
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It is so great to be here and it's is amazing to see so many familiar faces, both participants who have joined us and families, so thank you so much for contributing to the research to help us understand more about all the kids that we want to support better.

So what I am going to talk about will cover a couple of topics, it's a perfect transition from the amazing presentation we have just heard. I want to share with you a bit of insight into what reading is, how we break it down, how we understand it. I want to talk a little bit about how the brain supports reading in particular and I'll talk about what the knowledge base is about struggling readers including children with hemispherectomy, what we know about their reading skills and for assessments what kinds of pieces would you want to see in reports for professionals who work with your kids in a clinical setting. Then I think we will have time for some questions afterward so I really welcome any insights or questions that you might have.

So, just to get us started, I want to get us on the same page just thinking about anything you are thinking about listening or seeing, for language you want to think about receptive or expressive capacities as well. So there are always 4 skills we want to think about, never just reading in isolation but reading in a larger context of the other skills that are the counterparts. So if we think of information that is visual and receptive, so it's coming in to my system; that's reading. If I am thinking of something that's visual and I'm putting out into the world; expressive, that's writing, and if I think of it in the auditory domain, what's coming into me in the auditory domain, that's listening, that's a receptive skill I have and when I am expressive that is my speaking skill. So part of what a good clinician will do will be to contextualize reading in this broader framework of the skills that are available and I am going to have some transitions from a very simple model to make it a little bit more complex. I am also very happy to share slides and articles that I will reference afterwards, so in case you miss anything I will be very happy to pass that along.

So I am going to teach you an acronym that is very helpful to me, the acronym is PPOSSM. (Possum) Misspelled, I am prepared for that responsibility, but it is a very helpful way to remember some really important ways to break down what language entails.

So I am going to review each one to give you some definitions and some descriptions but just to give you an overview: When we think about language that is related to oral and to written elements you want to think about the elements of phonology, pragmatics, orthography, semantics, syntax and morphology. I said all those quickly; I am going to walk through each one, give you definitions and repeat them.

So the first one we will think about is Phonology. I will start off with the fun part, which is the cartoon here. In case you can't see it, it says, 'sorry I was looking for Valley Parking', hopefully that seems funny and the reason it should seem funny is because this guy is looking like he wants to be valeted. So Valet/Valley – the error there is in perception of the sound. The basis for language and the basis for reading does not start so much in the visual domain but in the auditory domain. That means that you have to be able to perceive the sounds of language in a way that is meaningful, accurate, sequential and precise before you can then map that system on to the squiggles on a page that we all agree are the letters we are going to use. So phonology is defined as the rules governing

the sounds of language. Phonology skills include things like rhyming, being able to match different sounds by being able to take letters that are separate and blend them together or to remember words with precision. So phonology one of the most important foundational skills for reading because it is demonstrative of your ability to master how sounds come together and how you manipulate them.

Then we have the next one: *P* for Pragmatics. No fun cartoon but I am sure you can think of lots of great examples here. Pragmatics is defined as the rules governing the use of language and how you communicate. So a couple of examples; it includes how you use language for different purposes, for greeting, for requesting, for informing, how you change your language depending on if you are talking to a child or an adult or a peer, or if you are adapting to someone's background knowledge or if they need more or less and also it includes followings rules for conversations, telling stories, taking turns, using your facial expression or reading someone else's or staying on topic. So I know for many of you that this is a domain that you may not have experience with on your IEPs or recognize it as as essential as the remaining ones, it is something that is important to have attention to.

So we have covered the 2 P's, now we are up to the *O* for orthography. So can everyone just read what that says down their? The Cat. It says The Cat and you are correct, great reading skills there and I hope you can notice that the middle letter in both of those words is exactly the same. So we have a letter that we read as an *h* in *the*, the same letter is in the middle of *c* and *t* and we read it as an *a*. That's your ability to be flexible with the written print of language and use context to help interpret what those symbols should mean in different places. So orthography is defined as the rules governing the written symbols of a language. So for our alphabet orthography dictates why we don't usually see a *z* and a *g* together but we often see a *t* and an *h* together. So this is a really core skill for our spelling but also for our reading because it is what allows us to know which sounds and which letters go together and in English there is not a one to one relationship between letters and sounds like in other language such a Spanish may have. That means a can make many sound and sound *a* can be written down in many ways, there is not a one to one relationship it is a much harder system to work with compared to other kinds of languages. So for kids the flexibility in learning the rules that govern orthography is another core foundational skill for literacy.

So for our next letter *S* for Semantics: Semantics are the rules governing the meanings of words. Now this is just not how words are defined, it includes any associations you might have with words, multiple meanings they may have. So if I say the word 'jam' you might think of your breakfast and what you put on toast, you might think of music jam sessions, some of you may unfortunately think of a traffic jam. All of the associations you have for a particular world are really powerful for kids because the rule of thumb is the more you know about a word the faster you can retrieve it. So a lot of interventions for reading actually train kids on having a lot of associations built up for particular worlds that are important for their vocabulary. You can think of this word, what else does it make you think of? Can you tag on a lot of associations so that there are a lot of access points to go in and get that word later when you need it? That thinking can be either in oral language or for reading. This cartoon here says, 'they complimented your driving – Parking Fine'. So this is a great example of how 'fine' has multiple meaning and he interprets it one way and his mom maybe a different way. Here is another entertaining one: This says, Lassie get help and lassie gets some help. So happy ending.

Our next *S* – our second *S* is for Syntax. Syntax is the rules governing the organization of language. So when you are putting words together in sequence you are following rules of syntax. So that includes how you sequence and organize language, how you match nouns and verbs, how you use pronoun's. I have got some examples of syntax that are violating the rules that we have, might be familiar to some of you. I have met in our assessment sessions

many Star Wars fans and maybe they will appreciate this also. 'Truly wonderful the mind of a child is', you can understand how that is understandable but that the syntax violates the rules that we use when we communicate. 'Judge me by my size, do you'? I thought both of those might be appropriate for this conference, so those were hand-picked just for today.

So the last letter in our acronym PPOSSM is *M* for morphology. A morpheme is a smallest unit of meaning in a language. So when I refer to myself and I say 'I', that letter actually is a morpheme because it has a meaning by itself. If I want to change the word 'run' to 'running', the ~ing is a morpheme because it changes the meaning of run. So all these units of meaning in a language help us enhance how we communicate. So morphology is the rules governing the use of morphemes. So here I have some common types of errors involving morphemes: 'My dad drink tea', instead of 'drinks tea'; 'somebody coming', instead of 'somebody's coming', 'could I finish game', instead of 'the game', etc. So these are the kinds of ways you might pick up on those morphological errors in conversations or observations you might have. Here's another example: Here is a school nurse and she is saying, 'I'll put some gauze on your cut', and he is saying, 'it's a small cut so I think it will only need one gau'. That's a great example of how developmentally morphology takes its time to tack on in a way that is not overgeneralizing some of the rules that kids might be learning.

So we just talked about *PPOSSM* (Possum) and I am going to organize that for you into this framework to help you think more about how all those pieces hang together.

So you can think of language as having form, having content and having use. So when you want to organize PPOSSM further you can think, when I think of content I am referring to semantics, when I think of use I am thinking of pragmatics and when I think of form I am thinking of those elements that dictate how you put it together. So that is the phonology because that is how put together the sounds, the morphology; how you put together the morphemes and the syntax, how you put together the words and all those pieces overlap. So far so good?

So I am going to continue complexifying it a little bit. So the next thing now is I'm going to bring in a figure that helps us expand what we are thinking about. So, I talked about PPOSSM and actually just to think about that, which aspect of PPOSSM is missing from this slide? The *O*. Exactly, *O* for orthography because the orthography is the only element specific to written language because it is about letters and print. The rest of these are important for both oral and language and orthography is the only one you need for written language. So with think of orthography and all the piece that it comes with, we can now blow that picture up a bit bigger.

So you can think that the ultimate goal of reading is to comprehend what you are reading and to be reading at a pace that supports your comprehension, to be a fluent reader. Ultimately that is where you want to end up but it takes a lot of complex interaction of skills to get there. So those skills we can think of around the language side, language comprehension and word recognition. So there are 2 really distinct categories that will predict your reading outcomes and your reading comprehension.

One is how skilled are you at understanding oral language and using it? The other separate skill is how able are you to look at letters on a page and know what sounds they're matched to? Now that top category has a lot of elements that go into it. Your language comprehension includes your background knowledge, your vocabulary, how deep and how precise it is, your awareness of syntax and semantics, your ability to reason verbally, to make inferences, understand metaphors and to just know about literacy knowledge in general. How do you open a

book? How do you use it? That sort of thing, what different genres might include. As all of those skills become increasingly strategic you are on your way to becoming a more skilled reader but that is only with the counterpoint available to you as well. From the word recognition side that means you have to be able to able to have intact phonological awareness because that means you are going to be able to break words down if you know the components of language and how to map letters and sounds onto each other.

The other way to read is instead of breaking every single word down is by remembering them in discrete units. Perhaps when you saw my last name you had to break it down if you braved to read it all systematically, that was not a sight word for you, you had to decode it to access it, you had to take your knowledge of sounds and map it onto letters. If you saw your own name you have seen it enough times that it is now a sight word for you, it is completely automatic. So there are some words that with enough exposure those get banked into an inventory that you can then access whenever you need to but in order to learn new words the skills that are most important for that are being able to decode because that means you will have the skills to access any word that is not yet in your inventory.

So with these 2 becoming more automatic and strategic those are the underlying skills that get kids to be comprehending readers. What is not here that are incredibly important skills that I just need to acknowledge: Attention, consecutive function, memory and visual motor and oral motor skills. So I will just put that aside for the moment, but I acknowledge that it is there.

I am continuing to build up your awareness of what it takes to be a reader and what kinds of elements are important that go into reading and there was an important report that came out of the National Reading Panel and these are the 5 most important elements for reading. So in your assessments that you should be looking for, these are the core foundational elements that you want the specialists that work with your kids to be able to speak to. One is phonic awareness, that is similar to what I mentioned earlier with engaging with the sounds of language and just that you are very comfortable with what exactly that means we can do a quick activity together.

Could you please say the word 'cowboy'?
Cowboy.
Could you please say 'cowboy' without saying 'cow'?
Boy
Now can you please say the word 'mixed'?
Mixed
Now can you say 'mixed' without saying 'k'?
Mist
I will do it with you. [Sounds out the word mixed]. So now we have 'mist'.

So I hope what I hope you found was that that was harder and what you had to do for that example was to not rely on the letters but only rely on the sounds and parse the speech stream, remove a distinct piece and then re-blend it together. That's the kind of activity that we sample when we are looking for phonological processing because we are looking for facility with using the sounds of language and being able to be flexible with those. Phonics is now taking the sounds of language and mapping those on the letters of language. Reading fluency, vocab and comprehension I think are more straightforward so I'll leave that there and I am going to transition a little bit and talk to you about how the elements I have just reviewed are supported with brain functioning.

So this is a schematic that helps us just start getting oriented. For those readers who are typically developing we most often refer to reading development in the left hemisphere it's not because reading is not important in terms of how the right hemisphere supports it but I tend to think of how in typical development the right hemisphere has a huge role in what I think of as the artistry of language. So, when you use your voice to emphasize something, when you're sarcastic, when you are making jokes, when you're using hyperbole or irony anyway that you are kind of adding that sprinkle or artistry to language. The right hemisphere has a huge role in that but a lot of reading research heavily relies on studying the left hemisphere because that is a core region for a lot of core language functions and also a lot of what I talked about before with decoding skills tend to be left lateralized. This is a general swath of what is involved for reading.

You can see in the frontal lobe, executive functions, a little bit behind that speech, a little bit behind tha auditory processing and then the visual piece and the integration of language and visual information. Now I am going to make that a little simpler for you but first I am going to show you what might be my favorite slide of the talk. I want to show you what a brain looks like when it's reading.

This is a typically developing reader reading a single word, it's an adult, and I want you to just appreciate how much of the brain is involved. You can see these huge swathes of activity throughout the brain. This is just the left hemisphere. You can see a lot of it is activated there is a bit of back recognition in the visual cortex and washing forward and so forth and now each of those regions that are coming up I am going to simplify it to explain how each of those plays a role.

Question: Were they reading out loud or just looking at it reading?
Joanna: They are reading a single word out loud.

So how did they do that? There are 3 main networks in the reading brain for typical readers. We think of the anterior system which just means front, and then 2 posterior systems. You may have learnt the words 'dorsal' and 'ventral', I will remind you in case you haven't: I think of a fish and a dorsal fin is on the top, so I think of dorsal as upper and vent, I think of gills which are underneath so I think of that as bottom. So these 3 core systems are interactive and part of a larger network.

The frontal system has a lot to do with motor production, processing unfamiliar words and those posterior systems; the dorsal system is heavily driving your decoding skills. So when you are seeing letters and you are trying to think of how they sound or we are trying to spell, that's the system that is supporting it. When you recognize words like your own last name, you are building off a part in the visual system that we're thinking of as the posterior ventral. So this is helping to also parse that. When you decode you are relying a lot on the dorsal, when you are recognizing you are relying a lot on the ventral.

So when we think of reading disability the most common one that people have researched is dyslexia so as a counterpoint I will just share with you what we know about dyslexia and relate that to a hemispherectomy. Dyslexia being the most common reading disability, we know that it is neurobiological in origin and it is defined very specifically as having difficulties in the accuracy or fluency of single word reading. That means that you can see words in isolation and have a lot of trouble in either being accurate in how you are reading them or you can read them accurately but be extremely slow and not know how to be more efficient or faster at doing so.

A lot of the difficulty in dyslexia is attributed to difficulty with phonology. So that sound system we did before with 'cowboy' and 'mixed', those are the examples we are thinking of. Those core skills that you want in using the sounds of language if they are impoverished in some way there are going to be difficulties in mapping that system onto print.

If you cannot access words easily then a common challenge is in reading comprehension. For dyslexia you can never look at a brain scan and know somebody has dyslexia or not so it is only diagnosable from assessments. So the signature in the brain of dyslexia is that you tend to have hyper or more activation in the frontal lobe and you tend to have relatively less activation in both of the posterior systems so that means that the dorsal and ventral system are relatively less activated and that makes sense because in dyslexia what's hard for kids is decoding and recognizing words and what systems help support those skills? The dorsal and the ventral system.

The other really interesting part about dyslexia is not only are these the characteristics but in addition the right hemisphere is activated in the homologous or parallel regions as we see on the left. So those posterior systems are not only hypo or less activated in the left hemisphere but they are also activated in the right and you do not see that in typical reading.

So one interesting transition point then is a recent publication that we have for hemispherectomy: So we worked with some of the students some time ago and we asked the question: What is the maximum capacity of the right hemisphere to support reading and language? In dyslexia people talk about the right hemisphere but they always refer to it as compensatory without having a really good understand of what that means. What exact functions can it parallel? What exactly can it offer? Is there a ceiling to how much it can do compared to the left hemisphere? All of those to my knowledge are not well established or well understood. So one way we went about trying to understand that is thinking about kids who only have a right hemisphere and understanding and taking in account the complex medical history, can we get a sense of what their skill sets end up being? So that's what we did and we already knew from previous work that the right hemisphere has the potential to sustain ability and to improve ability and so I will share with you some of the data, so we will get to the good stuff first.

The first thing is here; in this study we published information comparing those with left hemispherectomy and a matched group of kids with dyslexia. So, those with hemispherectomy are in the blue; those with dyslexia are in the red. The first thing you might notice is that there are for example, a couple of categories where there's not that much difference between those with half a brain and those with the whole brain. Those with the hemispherectomy and those with dyslexia. There are extremely different mechanisms and pathways that lead to their performance but for some of these categories including timed real word reading and timed pseudo word reading there were not significant differences between the groups. Our samples were quite small for obvious reasons but you can see on the y axis for reading real words those with hemispherectomy were hovering just below 80. Our average range is 85-115. Those with dyslexia were hovering just around 80 and then there is not that real difference between reading real words and reading made up words for those with hemispherectomy but a little bit of an improvement for those with dyslexia. Passive comprehension was an issue for both groups.

The interesting thing was we took that exact group but instead of showing the hemispherectomy group compared to those with dyslexia, we broke it up by kids who either had an early or late insult, So this is the exact same hemispherectomy group but now broken up. The dark blue is early insult, the light blue is late insult, and now you can see that average really was capturing the exact middle ground of where each of the groups was originally. So now we are seeing for example, that the kids who had early insult in the hemispherectomy group are trending

to show stronger performance than the kids who had late but also those who have dyslexia. So this is a really interesting way of thinking about, how is that possible?

The particular tasks I am highlighting are timed word reading. Many of you may have experience of working with your kids and thinking that timed pieces are much harder and you avoid that and untimed is much better and that is the strategy. This again, is a compilation of lots of individual data but there is an interesting hypothesis that has come out of the work which is in some cases, for some of the kids we worked with who had had hemispherectomy, it could be possible that the timed element adds something that you can't get otherwise, that is it forces the system to be productive in a way that without the time pressure you won't get the same performance. So put another way: When we think about the general processing of left hemisphere and right hemisphere, one rule of thumb people think about is the left hemisphere can be more detail oriented and part oriented and the right hemisphere can be more whole oriented. So forest for the trees as opposed to the trees for the forest. If you only have a right hemisphere one strategy that you might be capitalizing on is reading words on a more holistic level.

Audience: Can I interrupt you? Can I ask a question?

Yes.

Audience: Could you define what is considered early and late?

Yes, the stroke or the surgery?
It is a stroke. It's a stroke.

Audience: Early stroke/late stroke or early surgery/late surgery?

It's a stroke. Early is before age 3. Everyone had the same question, that's amazing!

Audience:The more forest/more trees analogy: If you have remaining right hemisphere you are more likely to have more….

Forest.

Audience: So if you have remaining left hemisphere you are likely to have more trees.

Well I would put it this way: I don't know for the hemispherectomy cases I would be interested to test it, but I think the rule of thumb for the typically developing brain if you are asking to engage in different tasks, the right hemisphere is going to really be driving or supporting tasks that help you recognize the big picture, or the big concept, or the overarching umbrella themes. The left hemisphere is tending to be associated with more detail oriented processing. Other questions?

So one thing I wanted to share is that averages are great but really each of us really ends up caring about a child at a time; in an education setting, in a clinical setting, so what I wanted to share with you was a bit of a demonstration of how individual kids who were in that research, how their skill profile showed up.

So these are each of the kids who had early insult. So before age 3 most of them in utero. So the first category is receptive vocabulary. I say a word and you point to 1 of 4 pictures showing me which picture showed that idea. Reading real words – that's what word id is. Reading made up words – that's what word attack is and then doing each of those in a timed way. So a timed real word reading, timed made up word reading, and the last category is reading comprehension. So you can get a sense that there is a lot of scatter there are a lot of really different profiles where those skills can end up being. One thing that you might take note of is that some of these kids, if you are comparing the untimed word reading to the timed word reading, for a lot of these kids that timed word reading actually is a little bit elevated compared to the untimed word reading and that is what I was referencing before about how the right hemisphere might have a proclivity to this whole vs part processing that is supporting it and when you are in a timed context you don't have time to either second guess yourself or to force yourself to use a decoding strategy or to take your time and second guess or really think a word through. If it is available in your inventory, whether you have confidence that it's there or not, it's coming out. So that is kind of one way we are hypothesizing the explanation there.

So this is the early insult cases and these are the late ones. So again, on the axis which you can't see (so sorry about that), the axis starts at 50 and it goes up until 110, so a lot of these scores are hovering in the 50-70 range but you also see some of these kids have that same pattern with the timed word reading having some elevation above the untimed word reading that I think parallels what we have just seen. Any questions or otherwise so far?

For those of you who have come for the reading study and assessment while we have been here with the team, a lot of these are the kinds of assessments that we have done with your kids that we are looking forward to giving you scores before the end of the summer.

Audience: Will these slides be available?
Joanna: I am happy to send all of these slides. Absolutely.
Monika: I'll put them on our website.
Joanna: Perfect.
Audience: All these kids were stroke or..?
Joanna: These kids were.
Audience: So I guess something like Hemimegalencephaly would that be an early insult, it was in utero?
Joanna: Yes. All of these were in utero and then all of these were [---] [31:30] encephalitis.

[---] inaudible [---] [31:32 - 31:50]

So, what I wanted to transition to, to make sure we cover it as well, is this assessment piece. So I am now going to revisit some of the concepts that we started off with when I talked about what goes in to reading. I followed that up with showing you how the brain supports those kinds of skills, I have a little bit about what we've learned so far about kids with hemispherectomy, so this is going to be hopefully insightful for whenever you're reviewing reports or working with clinicians who are going to be working with your child. I have to say one of the most incredibly helpful things that those families I have worked with this time is that no one knows you child better than you obviously, and you're insights about how to optimize and really support them in testing session is really invaluable and I hope that is something that you continue to communicate with people who get the privilege of working with your kids.

So first I will share that assessment is not the same as testing; testing is just giving a set of questions to get a score, assessment is combining data from multiple sources. That includes observations, parent reports, the tests themselves and professional judgment. So we think of these 4 pillars of assessments – you have norm reference tests, that means that there are norms that you can then translate a raw score to an age or grade based comparison. Interviews with the teachers or parents, observations in the classroom and informal assessments. So of these might be pieces of data that go into a diagnostic eval for your child. Qualitative observations should be in a report. So that means any report should not just have scores, it is incredibly important to complement quantitative information with qualitative, so what does that mean?

You should have a sense of what kinds of strategies or problem solving approaches were used for different tasks? What was the persistence, the flexibility or the frustration tolerance like? How easy was it for someone to give up and under what circumstances? Does using multiple choice improve or make performance worse? Is there a difference on expressive tasks vs receptive tasks? Do errors appear to be because of inattention or impulsivity? Do certain tests seem especially effortful or stressful? And are there some tasks that might elicit enthusiasm or enjoyment or withdrawal or reluctance? So getting a sense for how the qualitative piece is for any assessment is as important as the numbers themselves because that will really be able to inform practice as well.

Just to give you a sense – some of this might be quite familiar – whenever we are doing testing there are a couple of numbers that are going to be essential for your understanding. We get raw scores but they are never useful in their raw form. So if I just tell you for a given test a child got 15 that doesn't mean anything, it is not interpretable, so what you are going to be interested in is the interpretable scores. One of them is the standard score. The standard score I mentioned a little bit already, it is probably the most widely used, has an average range of 85-115 most often and some manuals vary in what they are categorizing as average, below average or otherwise. Another number that is going to be very important is the percentile ring; so relative to the norm group it tells you what percentage of people in the norm group performed more poorly than the individual and probably I think the most relevant for this group is that they go age and grade equivalents. So these are referred to as a hypothesized average score of children of a particular age or grade level. If someone has an age equivalent of an AE or 5.6, that means their performance was commensurate with a typical student of 5 years 6 months; if someone has a grade equivalent or GE of 6.1 that would mean that their performance was commensurate with a child in the first month of 6th grade.

So what kind of elements would be really important in assessment? These are some of the highlights that I thought might be useful. One is getting information on general cognitive abilities. Now for a lot of kids who have a very scattered profile what would be important is to not look at composite scores or scores that collapse across sub tests but instead to look at individual sub tests themselves because when you have a child with a very varied profile any time you are looking at a composite or a combination across sub tests you are really missing and obscuring information that might be quite useful. So I would just caution against that piece.

So, we will walk through each of these. Phonology is what I mentioned earlier; there are many theorized assessments of functional processing and those really are going to be a hugely helpful predictor of reading capacity. One task that we will review now is rapid automatized naming or RAN, we will practice that one in a minute. Then I mentioned when we started that reading should always be in the context of language, it is just 1 of those 4 quadrants. So a reading evaluation should include the kinds of skills that you care building off of to read: Your core language skills. So measuring vocabulary and language use and understanding are incredibly important.

When you measure word reading there are 4 dimensions that are important. Measuring real words, measuring made up words and then timed and untimed because comparison across those 4 is very revealing for someone's skill set as well. Then there is reading comprehension.

So just walking through each of these categories a bit. One common test you might see is the Wechsler Intelligence Scale for Children, or the WISC, and it breaks down cognitive abilities into these categories: Verbal comprehension, visual spatial, working memory, fluid reasoning, and processing speed. Describing each of those is not so relevant right now but I think as a base line those skills are important to document and not obscure so much in the composites.

It is just an example to show you: The top figure goes with the one next to it, just like which one of these goes with bottom figure. So you are doing a lot of these visual analogies, this is one way people measure non-verbal IQ. So it does not require a language processing except for the directions and it is about pattern recognition. The WISC and other tests like it will help identify key strengths and weaknesses that are related to learning, cognitive function and attention and no literacy skills are required, so none of these involve reading.

For any child there is always going to be relative strengths and weaknesses, that means that for anyone who is getting an assessment done, a clinician should be able to tell you that not everything has a deficit but what the counterparts are as strengths and those strengths don't have to be the ones that are very high scores, it could be that there are lots of low scores but relatively speaking strengths and weaknesses should always be identified within any profile.

Phonology I mentioned earlier so I'll just reference that and just keep going. So Rapid Naming – this is an activity we will do together. I am going to invite you to take a look at this. You can start in the far left and read across each row as quickly as you can without making any mistakes.

[Audience reads]

OK, I promise in a real setting you would not do it in a chorus, it would be one on one and hopefully a quiet nice environment but what you just did was you looked at abstract visual stimuli on a page and you sequentially, in the same way that you read, from left to right, top to bottom, you analyzed them, you perceived them, you named them, you articulated it, you shifted, you went to the next one, and you did that repeatedly throughout. So this is a really predictive assessment of reading because it is said to parallel the same exact sorts of skills in a much more simplified way where you have to do a reading test. So phonology and rapid naming or RAN tasks are 2 of the core component skills that people look for predicting reading outcomes and it is also another one of the most common deficits for those with dyslexia.

So I mentioned earlier that you would also want to also have word reading for real words and made up words both in timed and untimed contexts. So a common assessment people might use is the [----] mastery test and for the timed reading the common test that is often used is the test of word reading efficiency. So here is one example of that one. You can see on the left is real words, on the right is made up words and so I need you to start at the top and read down the list as fast as you can without making a mistake. So let's do the real words.

[Audience reads]

Ok, now let's try the made up words as fast as you can without making mistakes.

[Audience reads]

OK, so that's what the kids go through as well and that gives a sense of this automaticity piece, so you don't have time to second check yourself, you don't have to decode, you're just kind of pushing though so in a way it is almost bypassing what might feel like roadblocks otherwise to kind of reveal what is in there when you pressure the system to see what is in there to get it out.

Then passive comprehension can be measured in a whole range of ways; one example is that people read a sentence that has a missing part and you fill in the blank. An example is taken from the same measure I talked about earlier, the WRT passive comprehension sub test.

Vocab is incredibly important, so this is the kind of task where you are shown 4 pictures and I might say, 'bicycle' and you have to point to the bicycle. So that's a task we are using today when we are doing our assessments that gives us a baselines for receptive vocabulary.

Then another example of oral language tasks might be, I am going to say a sentence and I want you to repeat when I finish.

I run.
I run.
The assignment was 14 pages long….

That's kind of an example there, so the goal is, can you perceive all of it, hold on to it, remember it and then repeat it back in a precise systematic way? If you can't are you holding on to the meaning or is everything just falling apart? So those kinds of assessments are helpful for revealing all those elements of how language is processed.

So, I am going to pause here so we can have some time for the panel discussion and some questions that come through from you and the headlines I would love for you to walk away with are thinking that reading abilities can be understood in the context of cognitive and language skills, that reading abilities can really be thought of as having component skills in phonology, rapid naming, and then you can think of outcome skills in word reading, comprehension and writing and that is one way you can think about what is in assessments, and if they have been covered. And that these component skills are incredibly good predictors of reading skills and insights into these areas will be really helpful for formulating the best kinds of education purchase for the kids. So thank you to the participants and families in these studies and this visit, to the lab members, and the NSF and [---34:49] supporting work. Thank you.

Audience: Would any child that has had a hemispherectomy have dyslexia?
Joanna: Dyslexia tends to not be diagnosed in the presence of something else that could explain their difficulty. Dyslexia is a challenge in single word reading but it is often not given as a diagnostic label when there is a more dominant frame of reference that can be helpful. That does not mean that you would not earn on IP the labels that

are helpful. So dyslexia is actually a term that is most often used in the research world and if you look at what clinicians use, they use a manual called the DSM and what educators use, they use IDEA. So the Federal Law that obligates you to get services in a school setting would not say dyslexia, instead the parallel term is Specific Learning Disability and then that category has 6 options. So if your child is getting reading services in a school most likely they have an SLD categorization and then the 6 categories, the first one is essentially parallel to dyslexia which is single word level deficit. The second category is reading comprehension, the third and fourth are about math; one about math computation and one about math reasoning and the last 2 are writing relating, one is about spelling, one is about written expression. So on IEPs in education contexts the relevant term that people need to use because that's what gets your services, is Specific Learning Disability and then people sub-categorize into one of the six categories that are published.

[----Inaudible 45:47----]

Yes, that is entirely true. So it you wanted to think of the most productive community partnership to think of resources that would be beneficial the dyslexia world I think for sure is a huge one. The dyslexia world has an organization in almost every State so local state branches of the International Dyslexia Association have a really helpful resource. If you check in your State to see if you have a branch and if not then you'll have one close by, they almost always offer free or for $20 membership, free consultation on IEPs, free recommendations for clinicians who can do evaluations in your area, free referrals to local places to get intervention services. The International Dyslexia Association – and we put together a resource page that we have been giving out to families who have visited us but I am also happy to email that out so you all have it. So the International Dyslexia Association or IDA has a branch in almost every State and it is a great resource for directly talking to the Board members for referrals or consultations and also for accessing resources regarding exactly which kinds of interventions are available and which ones might be a good fit.

[---Inaudible---]

We just are finishing data collection right now. So what we are doing now, we invited families who had either situation and will be looking forward to just actually having the counterbalance, to understand both communities and see what we can learn about how they compare.

[---Inaudible---]

I hope with our next paper, because of your participation in the research that we were here for that can change. We are really eager to offer as much information as we can and it is all because of you bringing your kids to us and them joining us.

[---Inaudible---]

So the question is is there a specific program you can recommend? So one thing I will say is that without knowing the individual kids it would not be a helpful recommendation because it should be based on each child and in what context their performance is in, both cognitively and with their language skills. One thing I will say is that one hypothesis that I was referring to before that for some of the kids who only have the right hemisphere, if it is true that they may be benefiting from an approach that's a bit more whole vs part orientated what that translates to for instruction is supporting their recognition of words in bigger chunks or being able to visualize

words in a way that they can access. That's in contrast to approaches intervention wise that would be more always decoding based. So that's really dyslexia, it's a parallel story, because you're balancing intervention that teaches kids to decode every word with intervention that supports kids with recognizing words and building their sight word vocabulary. So for example, a program like Lindamood-Bell Seeing Stars supports this kind of visualizing words and kind of increasing the chunk size of the words themselves. It's going to be worthwhile to help kids be able to decode because that means they have access to new words across the board but in particular cases, given different kinds of strengths or weaknesses, considering supporting this potential strength with the more chunk oriented recognition pieces that might be something that could be helpful.

[---Inaudible---]

My email address? Jac765@mail.harvard@udu

Audience: It's something you probably can't answer and I am hoping you can maybe just give me a generic guess. My daughter has never read, she's 10. When she was 4 she knew most of the alphabet and could count and seizures got bad. When she had surgery she knew no letters, no numbers. She is now learning letters and numbers again albeit 2 years and we are still working on counting to 10 and stuff like that. So, do you have an opinion (and I know if it is only an opinion) on if she may ever read? I mean, again, she is 10 years old now.
Joanna: I don't know that I am in a position to answer that.
Audience: As an opinion.
Joanna:I will say that what it makes me think of is for a lot of times when we work clinically with kids who have a lot of trouble just accessing that text/speech relationship, that letter sound correspondence, one thing we think about especially as they get older is giving them functional literacy skills and that is a different direction than trying to support them with the more core literacy skills that you start off with for lots of other kids in elementary school. So if you go more of a functional literacy approach what you are doing is giving them skills that you anticipate will help them navigate the world with some independence and some safety. But it is very much focused on things that will be practically helpful in a very concrete way.

[---Inaudible---]

I think all the experts for that question are among you. Each of you who have gone through that experience will be able to speak that concretely to say, 'in our situation…' I talk with some parents and some people shared that right as soon as they woke up they were speaking and that was a surprise and a welcome one and others who had different stories. I don't have any insights that would be science based and I think at this point I am not sure who knows how to predict outcomes and I think the physicians and the surgeons and the families who have gone through it have more authentic, real world experience that I don't have about that.

[---Inaudible---]

I am going to stick my neck out a little bit and I am going to say he may read great, he may have some issues, he may have some significant issues or he may not read. So I think you hope for the best, prepare for the worst and use our resources afterwards and we will all do our very best to push him as far as possible but I don't think there is an answer or a crystal ball unfortunately to know for sure.

What I think would be amazing is, to my knowledge, I don't think there is a lot of assessment before the surgery in terms of academic skills. To my knowledge, I think there are so many other complicated medical pieces that have people's attention. One of my research wish list items would be to have assessments done on kids before and then you have a comparison to think about after and I can imagine numbers going in all sorts of directions, the procedures may have been inhibiting learning and memory and so forth and you can see it going in any which direction.

[---Inaudible---]

The question is what grade level is considered functionally literate? I would say aiming for – we are in the elementary school age range, and it is requiring that you recognize basic words. I would say the upper limit of functional literacy level might be fourth grade, so if you can get a child to a fourth grade level that would be a great place for them, they would be able to navigate a lot of information that they'd be exposed to in the world. Then wherever they may fall before that, aim for that and see how things go.

[---Inaudible---]

In the public school setting the best person to do a reading assessment, I guess the answer ends up being who is doing it in a school and I guess the most likely person is usually a school psychologist. So those of you who have been in school settings, have other people done it sometimes, like a speech language pathologist might do it? So I guess what you want to have is someone who understands reading. Some speech language pathologists also have been trained in literacy but it is not common so an ideal situation would be an SLP who has done also literacy training who can then understand the language and the literacy and how they interact, that would be one really ideal approach. Another would be by a school psychologist who has studied and understood reading disabilities and even if it's not hemispherectomy, at least understanding reading development and atypical development and how to understand it.

[---Inaudible---]

Do you mean me in particular or in general? In general. So the question is do testers or people doing the assessments accommodate for the compromised visual field perception right?

So one thing that we have learned every time a family came to work with us was included in their description of what might be best for their child was exactly how to orient things and position things so the child can perceive them. We did a very gentle visual test as part of our assessment. In the settings where you're getting clinical evals I think that is absolutely essential to educate people on what to do and how to do it. A lot of people, the majority, will not have experience of working with kids that this community includes and I think sharing your expertise on exactly what works for them including the visual piece is a very easy way to support them. So in terms of additional accommodations or otherwise, because we want to understand how they might function on other kinds of activities or contexts assessment tries to replicate what you might be seeing in lots of other places. So unless there is some way in which everything in their visual field is going to be changed in some way, using assessments that are going to be similar to what they might experience if they walk outside the room is one way to know what it will take and how they will be functioning in the real world setting. That's one explanation to think about. Not adapting it in a very extreme way is actually a good way of making sure you are getting a sense of how they might function when they step outside the room.

[---Inaudible---]

So, great question, is it possible that kids might benefit from reading from top to bottom as opposed from left to right? There is a really nice pearl from the dyslexia world that speaks to this. One study has found that those who have dyslexia study with print and one technological intervention that's quite useful and affordable and easy to implement is that if you look at a tablet you have quite a few number of words on a given line of text. So one study showed that if you restrict how many words are on a line to about 3. It's a scrolling thing, so it's OK, you don't have to have everything printed out on paper and do this with reams of paper. They found on a technological device, you restrict the range of the number of words on a page to about 3 per line, one thing that was found in the dyslexia world is that it really helped kids improve their accuracy and their comprehension and that might be a really nice translation from the dyslexia world to explore for the kids here because instead of having to change everything about the words, instead you are restricting it in a way that is possible for whatever works for them. For those who are interested in how to access that or how to actually do that I can share with you the article and the colleague who is evolving the app for that, so in case guess that might be of interest to you. I'll send that to Monica as well.

[---Inaudible---]

There you go, some of you are already doing that it sounds like.

[---Inaudible---]

I think the app has several options for font style, the font size, I think the app also has the option for it to be read to you should that be helpful, so I would be very happy to share that as well.

For more information on neuroscience and implications for assessments after hemispherectomy, go to www.brainrecoveryproject.org