

When They're "In There" Somewhere!

Helping your child retrieve the language he knows! Part 1

A language retrieval disability is a serious, and seriously-misunderstood, challenge!

Kids who struggle with this hidden difficulty are significantly debilitated. They have language in their heads they can't get to, and people around them don't realize what's wrong! When kids face a retrieval crisis and *don't talk*, they appear disinterested...or defiant. They may even appear that they don't have the language in their heads at all. Yet

into our consciousness. We think, "Why couldn't I think of that word when I wanted it?"

As frustrating as it is, this "word-finding" difficulty is a minor inconvenience compared with the more serious form of language retrieval issue our kids often face. Yes, adults can experience it too, but it usually only happens after a stroke and left-hemisphere brain damage, in a condition known as "aphasia." Sufferers are often so frustrated by not being able to get to the words they know, they give up. We don't want this to happen to our kids!

Language retrieval, as a primary language disability, occurs in around 15-25% of our ASD kids. But all our kids experience it at a less-severe level while they are developing language. Because our kids' language is delayed, they all feel pressures to produce language – pressures that most typical kids never feel.

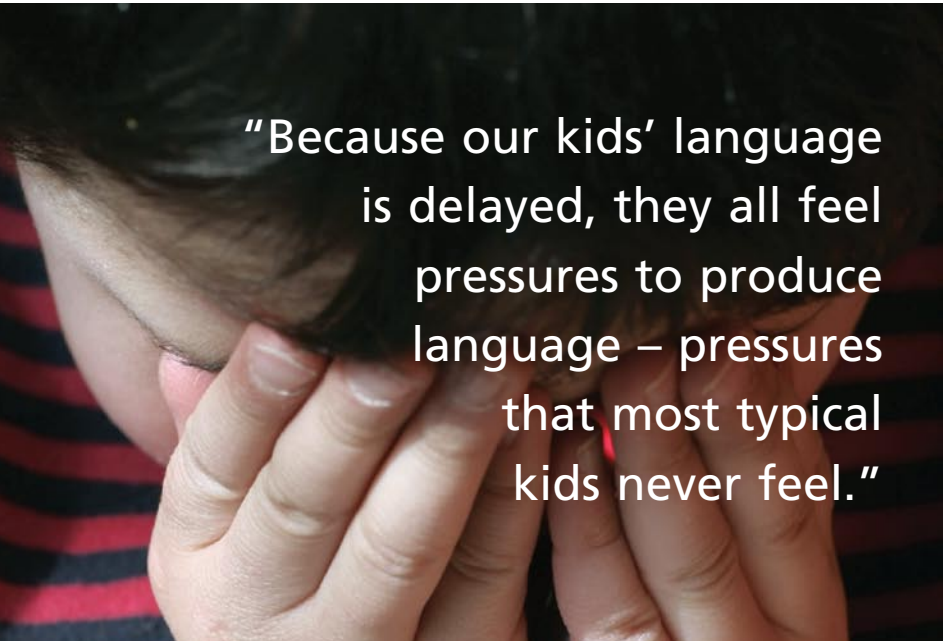
We don't want our kids to be discouraged in their brave attempts to communicate!

So, what can we do?

The most important thing we can do is recognize that our kids are struggling with retrieval. Secondly, we can understand what "language retrieval" is *not*. It is not willful avoidance of correct language. And, it is not "lost" language. If a child has formulated it before - not just "echoed" or repeated it, but actually formulated it - it's an emerging part of his language system. If you've heard it a few times, it's probably "his" and it's now "in there", in his head.

Our task is to help our kids access that language again, and to help them say it when they want to!

Yes, we know our kids are dealing with other challenges at the same time...regulating their bodies enough to talk at all, coordinating talking with other movement, motor planning speech itself, and forming the sound combinations of words. Sorting all this out takes a team of people who know your child well. Your child's SLP will be able to help figure out which parts are language (language development or retrieval), and which parts are speech (moving muscles for talking). If all this seems complicated to us, imagine for



"Because our kids' language is delayed, they all feel pressures to produce language – pressures that most typical kids never feel."

when such kids *do talk*, they use language that seems off-target or repetitive, and they may appear stuck in their own ideas...or defiant!

In this new column series, we'll explain what this means to you, and to your child with ASD.

First, let's take a situation familiar to us all - the "tip of the tongue" phenomenon. We *know* a word we want to say, but can't for the life of us, *find it* when we want it the most. It's only later, when we've relaxed our brain that the word pops



a moment how complicated it is for the children who are dealing with it!

Let's pause here for a moment and focus just on language retrieval, so we can really understand how it works. Retrieving is "finding" or accessing language that has already been developed (please see the Natural Language Acquisition column series in previous issues of the Digest, or at www.communicationdevelopmentcenter.com). We are not talking about speech development or speech access. For now, we are just talking about language retrieval.

In my 30 years of work with children, I have not found any language challenge as misunderstood as retrieval. It is a hidden challenge and often goes undetected; kids are seen as perseverative, set on only saying, or doing, what they want.

Hardly! Let's review a real life example of a girl I know to illustrate what I mean.

Colleen is a little girl I have known for the last year. Her seizure disorder renders her self-regulation and her access to the language in her head difficult. A year ago, at age four, Colleen could say some nice things when her regulation was optimal. The following conversation took place between Colleen and Megan, her SLP, at one such time.

C I'm a big lady.

M You are, and what a nice party you're having.

C Megan sit in the middle, and Alex...
wanna come with us?

But once her little brother, aged two, actually did join in, he demanded the clinician's attention, and Colleen's tenuous self-regulation was upset. Instead of nicely-formed language, she would open her mouth, and all that would come out was screaming, or the over-learned and over-used, "No!!" As things escalated and Alex didn't take "no" for an answer, Colleen reached out to her trusted clinician with ungraded pressure, "hitting" Megan and threatening the ambiance of the party.

Did Colleen still have the language skills to request her friend's attention? Yes. Were they "gone" once Alex entered the room? No. Colleen simply could not access them, or

retrieve them, under stressful conditions. Even after Alex was gently removed from the situation, Colleen's meltdown continued. But after receiving deep pressure and regaining calm, Colleen again exhibited her naturally sweet disposition, politely engaging her friend with a smile and her best language skills.

Did Colleen mean to scream or yell, "No!!" or strike out? Should any of her reactions be taken literally to be what she meant to say or do? Knowing Colleen over time, and under a variety of conditions, I truly don't think so. Rather, kids who have primary language retrieval disabilities have only their automatic behaviors, their "defaults," available to them when they cannot access their best language. If "No!!" is automatic, at least they have a word! The child who has no automatic language at all is at an even greater risk of being misunderstood, as his scream and ungraded "hitting" are often taken personally. When screamed at or hit, we often panic, and our own "default" patterns kick in!

We do have an alternative. Future columns will go into this in much more detail, and we have lots to share on this topic. But even now, faced with our own child's similar meltdown, we can apply what we have learned so far. Think "language retrieval" during these challenging times, instead of worrying that your child has lost skills...or is being defiant! Your child, in a retrieval crisis, will feel so much better when he hears you say, "I know you didn't mean that. I know you wanted to invite me to play again. I'm going to help you feel better now...then let's plan for the next time "Alex" joins our party!"

Your own little "Colleen" needs your help...in the form of understanding! Until our next column, dear readers, know that you now have a solid starting place for that understanding. All the best! ■

Marge Blanc, M.A., CCC-SLP founded the Communication Development Center, in Madison, Wisconsin 10 years ago. Specializing in physically-supported speech and language services for children with ASD diagnoses, the Center has successfully helped scores of children as they moved through the stages of language acquisition. Contact Marge and her associates: Communication Development Center, 700 Rayovac Drive, Suite 200, Madison, WI 53711, lyonblanc@aol.com, (608) 278-9161.

When They're "In There" Somewhere!

Helping your child retrieve the language he knows! Part 2

Welcome to our second column on *language retrieval*, a hidden challenge that affects all our kids sometimes, and some of our kids most of the time!

Recall Colleen, the four-year-old featured in our last column, who illustrates the dilemma of language retrieval...the disruption, the frustration, and the misunderstanding that ensues.

Colleen was hosting a tea party with her SLP, Megan, and everything was going well. She had orchestrated everything to be just right, and even invited her little brother, Alex, to join them.

You might recall the conversation:

C I'm a big lady.

M You are, and what a nice party you're having.

C Megan sit in the middle, and Alex...wanna come with us?

But once Alex, aged two, actually did join them, he demanded Megan's attention, and Colleen's self-regulation was upset. In a moment of dysregulation, Colleen went from using nice, multi-word sentences to the single word, "No!" closely followed by a full meltdown. She was, at one moment, the gracious hostess of her own tea party, and the next, the center of her own catastrophe.

Was Colleen being "bad," or avoiding using "her words?" Knowing her as we did, we could answer, unequivocally, "no."

Rather, Colleen was having a "language retrieval crisis." As a little girl whose retrieval challenge was her primary language disability, her day was filled with discrepancy. At her best, she sounded like a girl with only a mild language delay. She sometimes used nice verb tenses, conjunctions, and a plethora of nouns and proper names. But, unfortunately, those 11-word sentences, like the one above, occurred only occasionally, when she was well-supported by an adult who understood her mind, body, and linguistic system.

In daily life, Colleen could not be optimally-supported all day long, and her language output varied accordingly. Her

vocabulary suffered, becoming less-precise and more general. Words like "one" and "another" substituted for 'content words' like "cup" and "plate." And sentence structure suffered, because less-practiced words made up less-practiced (and more advanced) grammar. Under most conditions, verb tenses, and sometimes whole verbs, disappeared. An idea like that expressed at the tea party might sound something more like, "Megan sit here; Alex too" under more usual conditions. Colleen rarely "found" all the words she wanted to say (and

had in her mind), but, she usually got her main point across.

We knew Colleen well enough to know which words and sentences were in her head and which were not. When she talked, we instantly knew when something was affected by a retrieval challenge. And we knew that Colleen's best language, her language competence, included vocabulary and sentences like the following (with excluded words in parens): "Stand back and take a picture of my pony(tail). Now take a picture of my pony(tail going) the other way." Instead, when she was not optimally-supported and she actually expressed this particular thought, the request sounded like this: "Get off...I got my pony. Get off...I got my pony."

Yes, dear reader, there is a lot to think about here, and to absorb; please take a few moments to do so...

Let's continue to explore the discrepancy between expressive language *competence* (a child's developmental expressive language level) and expressive language *access* (a child's expressive language as it is actually spoken). We'll do this by looking at a few more examples of Colleen's language expression during the same time period.

Talking about her brother, Colleen noted, "He's grumpy actually every time." Even though Colleen used a nice 'content' word (and very descriptive!) like "grumpy," the sentence was not uniformly descriptive. "Every time" left a little to the imagination, and the listener came away with a feeling of





incompleteness, like there was more Colleen was about to say...but never did.

Another example is a series of sentences Colleen delivered as a story about something that had just happened. Note that none of the verbs have past tense markers, however, and other parts of speech are missing.

Ben come in.

Ben come in the big wagon.

Alex steal Alex seat.

The general gist of this story was clear to a familiar listener, but, this time, instead of sounding simply mildly language delayed, Colleen now sounded younger and less sophisticated than she was. So, not only was Colleen's specific *language challenge misunderstood*, but *she herself* was misunderstood!

To reiterate, a language retrieval challenge is a discrepancy between language competence and language access. And the priceless glimpses we occasionally get into our kids' minds, and into their language competence, help us truly appreciate their minds...and the myriad *access challenges* they face! Around our clinic, we take these "window" moments seriously, because they tell us what our kids are thinking about, their interests, what they understand about the world, and what their language development level is really like. These glimpses help *us* better understand *them*. And because our ASD kids face motor challenges, retrieval challenges, and regulation challenges, it is frequently difficult, and sometimes impossible, for them to demonstrate what they know! But special moments of tea party clarity help us see what kids are *trying* to demonstrate during all the other moments of their day.

Megan knew how to support Colleen's language access. When her mind (her ideas), her body (her regulation), and her linguistic system (her language development and retrieval) were supported, Colleen relaxed. At these times, she was comfortable giving herself the time to "search" for the right word, and to retrieve the one she was looking for.

Megan supported Colleen's language access by providing these basic things:

1. her undivided attention. She was accepting, patient, and, most often, quiet.
2. some judicious echoing back to Colleen of what she had said. Often, Megan just "held her place" for her with

a casual "Uh huh," so Colleen could "trigger" her own retrieval of the next words. Megan was careful not to reflect words back too quickly, but first, to give Colleen the time, patience, and space to search by herself.

3. a peaceful atmosphere that allowed Colleen to take the time she needed to search her mental dictionary for the right way to express herself.

In this way, Megan supported Colleen as she retrieved the word "truck" in the following dialogue:

C I have black...

M Hmm...

C I have big, I have big, I have big, I have big, I have big...

M Hmm...

C I have black big truck.

Yes, it can be agonizing to sit back and wait for a child to find her words. But, think for a moment about the alternative. If Megan were to become impatient, and start asking Colleen well-meaning questions, the pattern of the sentence that eventually "triggered" the intended word would have been interrupted. If Megan had asked, "What do you have, Colleen?" you can bet Colleen would have said, "I don't know," or she would have had to start over, or resort to changing the subject or saying something off-topic and over-practiced, like, "Hi, Megan."

Yes, it is hard to wait, and it takes some practice. But, you will be pleasantly surprised to find out that by simply waiting patiently, retrieval often works!

It is also encouraging that there are other strategies to use when your child is challenged by language retrieval, and we will explore them in our next column. But, for now, you have a useful place to start listening to your own child's attempts at "finding the words," and being poised to help! ■

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When They're "In There" Somewhere!

Helping your child retrieve the language he knows! Part 3

Hello, dear readers! And welcome to our continuing topic, **language retrieval** in our kids with ASD. Let's begin Part 3 with an important observation: *as long as our kids are in the process of developing language, they all will be challenged "finding" their language when they want it!*

In this column, we will look at how our kids struggle to find the words they want to say...and what you can do to help! Like little Colleen at the tea party we described in the first two columns, all children with ASD face the changing and challenging conditions of "real life" in ways most other kids don't have to worry about. Many situations create stress and "disregulation," and **finding the words to communicate** is the last thing kids can do!

As we think about strategies that might help our kids, let's first look at what adults do to mitigate their own word-finding "glitches." We all use "small talk" to buy a little extra time until a "lost" word pops out. A typical scenario to retrieve a person's name might sound something like this, "Wow, good to see you.

You know, it's been a long time. Nice to see you...Ralph."

As clever as our strategies are, we don't always have time to use them! Think about the well-considered and kind language we usually use with a child...until his safety is at risk! Then what comes out of our mouth sounds more like, "Sit down!!" or "Stop that!" When stressed or put on the spot, we really don't sound too different from our children!

Yes, we're all in the same boat, at least sometimes! So, our **best strategy** when our child is in a "retrieval crisis" is to

diffuse the situation. Increase the calm and maximize the squishes. Your child shouts, "No!!" or "Don't touch me!" and you know she can say, "I don't want to do that now." Remember that **those words are still in her head**, and please know that with time, your child *will* be able to access them more and more reliably! This is because you will give her appropriate practice using them under conditions that are

a little less dire! Keep reading, and we will show you how.

Some of you might have a burning question at this point. You might be thinking, "But my child uses 'movie talk' all the time! It's almost too easy for him to 'find' it! Is this 'retrieval'?" This is an excellent question, and to answer it, please refer to the 2005 Digest series, **Natural Language Acquisition**, to understand how echolalia fits in. Yes, it's natural; and, yes, it's part of your child's language development process; but, no, if your child is in an early stage of acquiring language, he is probably saying these words by picturing the movie in his head, and trying to voice-

over the sound track as he "hears" it. While this is a natural stage for our visual kids, it does not require language retrieval, as we're describing it here. *It will be awhile before your child has developed some original language (that isn't part of a sound track!) that he can then try to retrieve!*

Let's continue our detour for a moment longer, because, even if your child is generating original language, you will want to figure out which language is appropriate for practice! To prepare you to consult with a Speech-Language

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Pathologist to determine your child's "language level," please look over the language development sequence from the Digest series. It describes the six stages of language your child goes through.

So, when your child is ready, you will be ready to use the next strategy. You'll use it when you play with your child, at a time when you have a half-hour alone together, plenty of alerting and calming activities, and the potential for fun! **You will surround your child with the right language, the language that's at his developmental level.** If he is at the simple phrase stage, you'll use simple phrases that match his mood. You'll say things like, "Come on!" "It's here!" "Get it!" "Wow!" and "It's gone!" In this way, your child will hear and begin to produce **an entire level of language**, rather than just **particular** words or phrases. There is a big difference. If we ask kids to imitate words, say something scripted, or give specific answers, we have robbed them of the opportunity to *develop* and "generalize" language naturally, both at the same time! Yes, it happens simultaneously...even in our kids!

And I'll tell you how. First, you'll want to consult with a Speech-Language Pathologist to determine your child's language development level, and find out what other language is at that level. **Target language your child will like, and use sentence patterns from this level.** Avoid over-using the same pattern, because if your child "over-learns" it, it will actually inhibit retrieval of the language he wants to say. But by modeling an entire *level of language*, with a variety of sentence patterns, vocabulary, and contexts, the magic of natural "generalizing" happens! **Generalizing is built right into language development, if it's done right!**

So, let's see how this strategy influences retrieval. The more times your child accesses language at her competence level, the more this language will be available when the chips are down...and the stress is up! The more things your child says at the appropriate level when she is supported, the more solid her language will be when she goes to use it later.

But, in spite of your best intentions, **please realize that your child's best language will not be available to him very often!** It takes a well-supported situation, linguistically, physically, and emotionally, for that newly-acquired language to get used communicatively. And, this is hard to

pull off in daily life! More often, your child will be able to find the well-used words, common sentence beginnings like "I...", "It...", and, "Hey...", but not the specific vocabulary to end the sentences.

How do you help? The next **set of strategies** provides your child with a "scaffold" for getting to his words. When the time is right, try out the least intrusive strategy: *just waiting patiently* for the end of your child's sentences. Make sure you don't display any anxiousness, so your child can give himself the mental freedom to trigger the word he wants by himself.

The **next strategy** is to *repeat back the words your child said*, and wait for the end of the sentence. Make sure you are relaxed and patient, and that your child remains calm. A little physical activity helps take your child's mind off his challenge. If you can keep him from trying too hard, his target word might just tumble out!

But, let's assume your child doesn't get his target words when you wait. The **next strategy** is to go ahead and *provide the word you think he wants* in a casual, conversational way. It's better not to draw attention to his difficulty, but use the word in your own way. If your child says, "Hey, let's go to...you know, let's go to...", you can say, "We could go to... (pause)...the park...or we could go to... (pause)...the store..." Keep it light and open-ended, which encourages your child to take another turn.

Well, dear reader, there is much more to scaffolding than we've covered here, but the rest begins to look more like "therapy." We'll save the end of this topic for our next issue, and promise a story to tie it together! Until then, you have lots of food for thought...and, hopefully, some strategies to help your child "find his words!" ■

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When They're "In There" Somewhere!

Helping your child retrieve the language he knows! Part 4

Welcome to our final column on *language retrieval*! We promised you a story this time, one that ties together "real life" and retrieval therapy. Alan's story does just that!

Alan is a happy, bright, socially-engaged eight-year-old with ASD. Over the years, his family has provided him with everything they could, especially their love. Currently, his home-based ABA team helps support his inclusive first grade program, and structured peer play provides a scaffold to his relationships with his classmates.

Marissa is another character in Alan's story. She has known Alan for several years, both as his SLP and trusted friend. Marissa is so trusted, in fact, that Alan gives her the "scary monster" role whenever he wants to play his creative version of a chase and squish game!

Alan's history sounds familiar. He was diagnosed with ASD at age three, when he was not responding to his name, or to many directions. His expressive language was described as mostly "jargon," with some echolalic phrases here and there. In-home therapy began shortly thereafter.

Alan's family concentrated their energies in their boy's behalf...starting biomedical, behavioral, and other therapies.

And Alan progressed! But, in December 2003, when Alan was almost five, his family sought services with our clinic because they felt Alan needed more "stimulation to his verbal communication." His ABA team had taught him to follow directions, and to use several scripted phrases. Alan frequently made requests, using sentences like, "I want toys," "I want princess," "I want juice." And he also used some word combinations that weren't so patterned, "**Genie. Lamp**" and "**Color. Paper**" for instance. In this way, Alan commented on a favorite character, Aladdin, and suggested a coloring activity. Alan also used some more fluent sentences, such as

"Give me a hand," and "That's awesome," clearly gestalts he had heard said by others.

We could quickly see that Alan's language development was all over the map...and that he was clearly in the middle of acquiring language the gestalt way! Alan had done everything people asked of him, and other things on his own. But Alan was stuck...his language progress had come to a stop.

Our first task was to sift through the dips and valleys of his language development, and determine which language was still at Stage 1 (gestalts), which was at Stage 2 (mitigations), and which was at Stage 3 and beyond (isolation of single words, and original combinations). Although Alan still had one foot firmly planted in Stage 1, he had some nice Stage 2 and 3 utterances too. We found the patterned sentence, "I want..." especially problematic to making smooth progress. Alan had learned it as a whole gestalt, because he was in Stage 1 at the time! Then he had to work hard to use it flexibly because he didn't have the Stage 2 skills to do so.

We wanted to make Alan's life much easier, so we surrounded him with a nice variety of Stage 1 gestalts, making sure they were easy to break down and reassemble. This way, Alan had the opportunity to move smoothly to Stage 2. Alan

rewarded us by beginning to make steady progress! He was on his way to developing flexible, useful language.

But how did we know language retrieval was a factor? It was subtle at first, because kids have to develop some language in order to have something to retrieve! But once we became aware of Alan's useful vocabulary, we also noticed when he didn't use a particular word. The following illustrates a typical dialogue between Alan and his former SLP, Leslie, as Alan successfully retrieves the word "fish."

- A Ariel.
- L She swims.
- A Fish.





After a year of therapy, Alan's language was no longer stuck. He was producing rich, beginning sentences, with fluid grammar, such as, **"He's eat the tree," "I'm bouncing," "The door is open and close,"** and **"No, no, don't say, 'Nice jumping.'"**

Alan was also making progress with language retrieval. He had learned to rely on Leslie to help, as in the following dialogue:

A I want mermaid. No mermaid.

L The other mermaid.

A The other mermaid.

Yes, it took "reading between the lines." But the farther Alan progressed with grammar, the more he had available to him to work on retrieval, which turned out to be his primary language disorder.

Marissa had already entered Alan's life by then, soon becoming Alan's SLP. And, as his grammar continued to blossom, Alan was able to concentrate more and more on strategies for language retrieval. The following game was Alan's creation, with Marissa playing the requisite "monster" role. It is interesting that, in this game, Alan packed together some of the "real life" challenges that tax retrieval: social pressures, time pressures, and self-regulation. Here's how the game sounded:

"Freeze!" Alan shouted this as he perched at the top of the slide, and Marissa surprised him at the bottom. **"OK, now you can move,"** Alan continued, once he knew he was safe from attack. **"OK, you're frozen, so you can't get me,"** he then announced once he'd escaped to a safe place. But, when Marissa was almost upon him again, Alan's language access was back-to-basics, and he resorted to the universal mono-syllable, delivered at full volume... **"No!!"**

Thus, Marissa played all those elements of "real life" Alan could control with his words. Often, these words were retrieved fluently and his sentences were as complex as his linguistic competence. But, that was when Marissa was far away. Whenever she was about to "attack," however, Alan panicked and he could only "find" the reliable, but linguistically unsophisticated, "No!!"

In activities like this one, Alan was preparing himself for situations he couldn't control as reliably as his good friend, Marissa. Other practice opportunities came up naturally, as the following dialogue illustrates. Alan liked to hide from

his parents when they came to pick him up, and on this occasion, he invited a friend to join him. You will read how Marissa supported him:

M Mom and Dad will be here in a few minutes...

A We gotta ask friend if he wants to hide!

M Oh, yeah, let's go...

A We gotta find...um...um...what's this boy's name? Um...um...um...Jake?

M Yeah, he hid with us last week.

M We gotta find Marge and...

A Jason!

A Where's Jason? Marge and Jason are gone?

Marissa's strategies were these: remain unhurried, even though time seemed "critical"; acknowledge Alan's idea, even though it was not fully expressed; take multiple turns in the dialogue, giving Alan ample opportunity to trigger the name, "Jason" on his own; and, provide cuing as needed, without fanfare or pressure.

So, what's next for Alan? Retrieval challenges don't just go away, because even though grammar matures, vocabulary gets more complex. But, on the other hand, a child's mental resources also continue to grow! Alan is becoming a reader, and is starting to become aware of his ability to visualize what he has stored in his head. He and Marissa have started to experiment with this method of retrieval now, with some nice preliminary results. So, pretty soon, Alan, himself, may be able to answer his own astute question, the question he recently posed to his brother **"Oskar,"** Alan asked, **"how do you find the word?"**

From the mouths of babes! Have fun, dear reader, pondering this question...for yourself, and your child! ■

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Getting the Word Out

Language Retrieval Challenges

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