



# Why is it So Difficult to Get Treatment for Language Disorders?

by Sarah Wayland

I have two smart children who struggle to talk and understand spoken language. Despite their documented disabilities, it can be quite difficult to get them the treatment they need. I'm not alone; I know many parents who are in the same situation. It can be incredibly frustrating when your child needs help and you are unable to provide it. In this article, I will examine some of the reasons for this difficulty so that other parents can more effectively advocate for their children who need treatment for language disorders.

## Speech or Language Disorder?

Many people don't understand the difference between a speech disorder and a language disorder. Most think speech-language pathologists only work with people who stutter, cannot speak fluently, have difficulty producing certain sounds, or have trouble with their voices. These difficulties are characteristic of a speech

disorder. Children who have a language disorder have different characteristics. If they struggle to understand others, they have a disorder of receptive language. If they have difficulty sharing their thoughts, ideas, and feelings, they have a disorder of expressive language. The difficulties associated with language disorders are often more subtle than those of speech disorders, though they can be just as debilitating. Children with spoken language problems are also more likely to have difficulty reading and writing. Because many people have an intuitive understanding about disorders of speech, and seem less aware regarding disorders of language, we'll begin with an attempt to demystify language-based learning delays.

## What Can Go Wrong in a Language-Based Learning Disorder?

When describing language-based disorders, most clinicians focus on the five rule systems of language shown in the accompanying chart.



Five Rule Systems of Language

Rule System	These are the rules that govern...	Children who struggle with this rule system...
Pragmatics	What we say, as well as how and when we should say it.	Often say inappropriate things, seem unable to figure out what other people know, and have difficulty knowing when it is all right to introduce or change topics.
Semantics	The meanings conveyed by words.	Have trouble understanding the meaning of words and may have a limited vocabulary. They may also be unable to understand how words relate to one another. For example, a child may write "The apple hugged the tree," a statement which makes no sense because apples cannot hug.
Syntax	How words string together to form phrases and sentences. (Syntax and semantics are closely related. Some researchers argue that they should be considered a single concept.)	Have difficulty understanding that when words are rearranged, they can make new sentences with different meanings, such as: "The boy hugged his mom"; "The boy was hugged by his mom"; and "The mom hugged the boy." Each has a different meaning.
Morphology	Morphemes, the minimal grammatical units of a language which cannot be divided into smaller parts. (Morphology and syntax comprise what many of us think of as grammar.)	Would have a hard time identifying the two morphemes (cat and s) that make up the word cats, for example.
Phonology	Which patterns of speech sounds can be used in a given language and how they can be combined (pronounced).	Are confused by the way sounds change in different contexts. For example, the letter "t" in the word "to" is clearly pronounced in the phrase "to whom it may concern"; but it can be entirely missing in a phrase like "gonna work."



## Difficult to Get Treatment, continued

Breakdowns can occur in any of these five areas, either in comprehension (understanding what others are saying) or production (speaking). They can also occur in both the written and the spoken forms of language. So a child who can follow the rules of syntax when speaking, reading, and writing might be unable to understand these rules when someone is speaking to her. For this reason, language disorders can be quite difficult to diagnose.

### What Is a Child with a Language Disorder Like?

Kids with expressive language disorders struggle to convey their ideas clearly. They often know what they want to say, but can't seem to find the words. As a result, they use language that is vague and difficult to understand. They use generic words like "thing," "stuff," or "did it" instead of more specific words. Their speech seems to have more filler words like "um" to give them time to put their thoughts together.

Children with receptive language disorders, on the other hand, struggle to learn new vocabulary and have difficulty understanding questions and following directions. They can lag behind their peers in learning the words to songs and rhymes, and they may not seem to understand what they read or what others say to them. These children are often unable to recall the details of a story plot or a classroom lecture.

Other symptoms of language disorders may include difficulties with letters and numbers, including learning the alphabet, identifying the sounds that correspond to letters, recalling sequences of numbers and letters, and telling left from right. These children are often unable to memorize math facts, do math calculations, remember phone numbers, and spell correctly. They may also struggle with learning to tell time.

Children adapt to their language disabilities in a variety of ways. Some are quiet, seeming to prefer their own company to that of other children. These children fade away in the classroom, their needs unmet, falling farther and farther behind their peers. Because they are not behavior problems, no one notices until their lack of progress becomes catastrophic. Other children express their frustration more overtly by lashing out when they are unable to meet the language demands of the situation. These children can be labeled as behavior problems; and, if the language disorder is undiagnosed, they may be subjected to inappropriate behavior modification plans that never address the source of their disruptive behaviors.

### Language Disorders in Twice-exceptional Children

Diagnosis of twice-exceptional (2e) children with language disorders can be particularly challenging because of their ability to outwit testers. For example, my oldest child did not talk much when he was five, but he was a voracious reader. During his language assessment, my husband noticed our son reading the answers from the tester's worksheet which was in her lap. Once he pointed this out to the assessor, she hid the answers and the child went from scoring perfectly to not getting one answer correct.

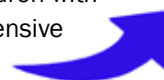
Because our perception of intelligence is often based on verbal ability, 2e children can be at a disadvantage. Show me a child who can respond quickly, express herself clearly, and use complicated vocabulary terms, and I'll show you a child who is likely to be labeled as gifted. On the other hand, show me a child who is quiet and often seems to misunderstand others or simply not hear them, and I'll show you a child likely to be labeled as slow. It won't matter if the latter child can solve complex visual problems or do higher-order abstract reasoning tasks, especially in the elementary school years – a situation that can be extremely frustrating for the child with a language-based learning disorder.

### Getting Treatment

Language skills increase in complexity as a child matures. For example, the skills required at age eight build upon the skills learned at age five. However, many children with a language disorder are unable to learn the skills on their own. Without explicit instruction, children who may be "average" at one point in time may not learn the new skills required of slightly older children. They need the help of a speech-language pathologist (SLP).

Finding an appropriate SLP takes some research. [See *the sidebar on the next page.*] Treatment has been shown to be most effective if concepts are reinforced multiple times within the same session, across multiple settings, and with varying intervals of time between exposures. If a child is exposed to a concept too infrequently, the delay may mean the child has to relearn the concept at each session.<sup>1</sup>

The duration of treatment is a decision best made by a speech-language pathologist familiar with your child. However, it's been my observation that children with language-based disorders often require intensive





## Difficult to Get Treatment, continued

treatment lasting many years. And that brings up this question: who pays?

### Will School Pay for Services?

As any parents who have tried to get the services of a speech-language pathologist for their children through the public schools can tell you, it can be quite difficult. A primary reason is the nationwide shortage of licensed SLPs. In addition, SLPs in the public schools are paid less than those in private or hospital settings.<sup>2</sup> Factor in the stress of overwhelming case loads – on average 60 to 80 children per SLP with associated paperwork<sup>3</sup> – and you’ve got a recipe for inadequate services. Given these factors, it’s the children with profound speech or language disorders who will be at the top of the list, ahead of those with more subtle deficits.

Furthermore, while schools are responsible for insuring that children can access their education, the schools also understand that the medical community (of which SLPs are members) is responsible for providing for the medical needs of the child. Schools believe that many of the services provided by SLPs are based on medical needs that are independent from the educational needs of the child.

Private schools are often unwilling to deal with a child who doesn’t seem able to keep up with the curriculum. While many private schools have SLPs on staff, the classroom teachers often lack training in how to accommodate children who have difficulty understanding spoken instructions and participating in classroom discussions. All too often, children with language-based

learning delays are asked to leave private schools or not admitted in the first place. *[For excellent advice on how to work with the schools to get treatment for language-based learning disorders, see the Wrightslaw website, listed along with other resources in the sidebar on page 7.]*

### Will Medical Insurance Pay for Services?

Although many health insurance plans claim to cover treatment provided by SLPs, it can be difficult for clients to collect payment. There can be legitimate reasons for an insurance company’s unwillingness to pay. For instance, some parents use SLPs as tutors for children who don’t actually have speech disorders or language-based learning deficits. It’s important to note that most SLPs don’t consider this an ethical practice, but it does happen.

Unfortunately, it’s been our experience that many of the reasons insurance companies cite for denying coverage are not legitimate. When your claim is denied, you have the right to appeal. The first step in appealing is to know your service plan benefits. Here are some additional tips:

1. Make sure you have the denial in writing.
2. Learn the proper appeal procedure for your insurance company and follow it.
3. When you talk with the insurance company, make sure to take notes summarizing the call. Include the date and time of the call as well as the full name of the person you talked to.



## Finding a Speech-Language Pathologist

Start at the “Find a Professional” section of the American Speech-Language-Hearing Association’s (ASHA’s) website: [www.asha.org/proserv/](http://www.asha.org/proserv/). Enter your location and the age of your child, and the search will return all speech-language pathologists who fit the criteria. Each listing provides information about the provider: contact information, type of treatment facility, information about payment and referrals, and disorders treated. Also helpful is asking for recommendations from professionals you respect, as well as from friends and contacts, especially those made through parental support groups.

Once you have a list of possibilities, you’ll need to call the providers and ask whether they can work with a child like yours. If you got the name as a recommendation, make sure the person is fully licensed and board certified. Sometimes a speech-language pathologist will not be a good match for your child. This doesn’t mean the individual is bad or that no one can help your child. It just means that you will have to keep looking until you find a provider you feel is right for your child.



## Difficult to Get Treatment, continued

4. If you exhaust the appeal procedures within your insurance company, find out what other recourse you might have. In some states, you can appeal to the state insurance commission.

Your strategy for appealing the denial depends on three things: your child's specific diagnosis, your policy's coverage, and the reason for the denial. The table below contains some common reasons for denying claims and some strategies for appealing them.<sup>4</sup>

The most important thing to remember about insurance companies is that they *want* you to give up. Just keep appealing.

### What Can a Parent Hope For?

There is ample research evidence demonstrating that treatment for language disorders is effective. In fact, a review published by J. Law and others in 1998 found more than 200 studies that report the



Reason for Denial	Appeal Strategy
Condition is of a congenital etiology.	For any of these reasons, you may need to change the diagnosis code to either a neurological code (340 to 349) or a coordination disorder code (315.4 or 781.3) and/or provide documentation that your child's specific speech or language disorder will not resolve on its own without treatment. Your clinician can point you to relevant published articles in peer-reviewed journals. Provide copies with each appeal.
Developmental delays are not covered.	
Articulation disorders are not covered.	
Public schools are responsible for providing therapy for school-aged children.	Your appeal should remind the insurer that public schools are only responsible for insuring that a child can access his or her education. Remind the insurer that IDEA does not provide for the medical needs of your child; this is why you have health insurance coverage. Because some states mandate different levels of coverage by health insurers, make sure you are knowledgeable about your state's insurance legislation.
Must result in significant improvement.	Some insurance companies require regular periodic progress reports. Have your speech-language pathologist document your child's progress at regular intervals.
Must be rehabilitation for a loss of previously attained level of functioning.	<i>Habilitation</i> (teaching skills that should be present) is usually interpreted as part of <i>rehabilitation</i> services. If you receive a denial of services on this basis, your appeal should mention the United States' federal rehabilitation services provision of 42 USC 300 e-1(1), which documents this interpretation. If possible, also provide documentation that your child's language issues became evident at some specific point in time or were caused by another, covered condition (i.e., after an infection or a head injury). Document the frequency, duration, and seriousness of the condition to the extent you can.
Not medically necessary.	Find out how your insurance policy defines medical necessity and address that definition in your appeal. The best approach is to call the insurance company and ask what's needed to prove medical necessity. It can range from providing the right diagnosis code and/or office visit code to getting a letter from a physician documenting the medical necessity of treatment. A Letter of Medical Necessity should include the appropriate diagnosis and code number; state that the diagnosis has a neurologic basis requiring intensive treatment by a qualified, experienced speech-language pathologist; and state how long treatment is recommended. Services provided by an SLP should always be referred to as <i>treatment</i> , not as <i>therapy</i> . (We get a letter documenting this on an annual basis from our developmental pediatrician and provide a copy with each bill we file.)



## Difficult to Get Treatment, concluded

effectiveness of language intervention for children with language learning disabilities<sup>5</sup> – so it can certainly be worth the struggle to get these services for your child.

In my own case, my oldest child's expressive and receptive language skills were below the ninth percentile when he was first assessed. We had to communicate with him by writing, and his favorite way to communicate with us was by forming words with magnetic letters. He couldn't play with other children because he couldn't understand them or tell them what he wanted to do. Within a year of starting an intensive course of twice-weekly treatments with a good speech-language pathologist, he was able to talk and understand others. Two years later he was performing in the low-normal to normal range on most spoken language tasks. It was nothing short of miraculous.

### Endnotes

1. Recommended Service Delivery Units by Type and Severity of Disorder. Illinois State Board of Education (1993). *Speech-Language Impairment: A Technical Assistance Manual*: [www.speech-express.com/advocacy-depot/speech-therapy-matrix.html](http://www.speech-express.com/advocacy-depot/speech-therapy-matrix.html).
2. *Bureau of Labor Statistics Occupational Handbook* entry on Speech Language Pathologists: [www.bls.gov/oco/ocos099.htm](http://www.bls.gov/oco/ocos099.htm).
3. Advocating for School-based SLPs: <http://www.speechville.com/advocacy-depot/caseloads.html>.
4. How to Work with Your Insurance Company to Get Coverage for SLP Treatment Services: [www.speechville.com/diagnosis-destinations/apraxia/insurance.html](http://www.speechville.com/diagnosis-destinations/apraxia/insurance.html).
5. Law, J., Boyle, J., Harris, F., Harkness, A., & Nye, C. (1998). *Screening for Speech and Language Delay: A Systematic Review of the Literature* (Vol. 2, number 9): [www.ncchta.org/fullmono/mon209.pdf](http://www.ncchta.org/fullmono/mon209.pdf).

*Sarah Wayland has a Ph.D. in cognitive psychology and studies how adults process spoken language at the Center for Advanced Study of Language at the University of Maryland. She is co-list owner of GT-Special, a listserve for parents of twice-exceptional children, where she has learned from the wisdom of others how to best help her children. She lives in Maryland with her family, including her husband Alan, her sons, Justin and Oliver, and two Fine Cats.*



Copyright © 2008 Sarah Wayland.

### Some Useful Language Disorder Resources

#### Websites

[www.wrightslaw.org](http://www.wrightslaw.org)  
[www.asha.org](http://www.asha.org)  
[www.speech-express.com](http://www.speech-express.com)  
[www.apraxia-kids.org](http://www.apraxia-kids.org)  
[www.speechteach.co.uk](http://www.speechteach.co.uk)  
[www.wordfinding.com](http://www.wordfinding.com)

#### Book

*The Late Talker: What to Do if Your Child isn't Talking Yet*, by Marilyn C. Agin, Lisa F. Geng, and Malcolm Nicholl, St. Martin's Griffin Press, 2004.