

Giving a Face to a Hidden Disorder: The Impact of Dyspraxia

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Giving a Face to a Hidden Disorder: The Impact of Dyspraxia

Debi J. Stansell

Abstract

Developmental Verbal Dyspraxia (DVD) is a disability with many names, yet it often goes without being diagnosed or treated. A neurological disorder, it involves motor planning throughout the body when the brain is unable to communicate directions to the muscles. With no obvious physical indications, it has been referred to as the hidden disability. Discussing the characteristics of dyspraxia in this article will, I hope, help teachers to recognize the possibility of this disorder, and ideally will act as a resource for possible interventions. As educators, we have a unique opportunity to help children reach their full potential, but we must first be aware of the special needs for the dyspraxic child that should be acknowledged and appropriately addressed.

Keywords

dyspraxia, apraxia, speech problems, speech delay

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Developmental Verbal Dyspraxia (DVD) is a disability that has many different names, and yet is virtually unknown. It often

goes without being diagnosed or treated. Specialists usually are able to diagnose DVD more by ruling out what it is not than by pinpointing what it is. Since it is difficult to diagnose, with no obvious physical indications such as a contracted hand or a limping gait, it has been referred to as the

hidden disability. My personal experience, however, has given this little known disorder a face, that of my beautiful 30 month old grandson. To the families of children with dyspraxia it is anything but hidden, and I understand firsthand the frustration and fear of

those families trying to explain to well meaning friends, medical professionals and teachers the challenges that a child with dyspraxia faces. This is not a child who is just a little slow to develop, or a child who simply hasn't acquired certain motor skills or speech yet. The child with dyspraxia is often a child who has above average intelligence who is attempting to cope with a real disability:"There are dyspraxics of all abilities and while some are very bright, no matter how good their ideas, they

cannot commit them to paper" (Portwood, 1999).

Having a child with a disability takes parents down a path they never dreamed they would travel. Their plans and dreams are

> different from the ones imagined during those expectant days before his birth. As Emily Perl Kingsley writes to depict the experience of raising a child with a disability, "... the stewardess comes in and says "Welcome to Holland." Holland?? You say. What do you mean Holland? I

signed up for Italy! I am supposed to be in Italy. All of my life I have dreamed of going to Italy. But there has been a change in your flight plan.... if you spend your life mourning the fact that you didn't get to Italy you may never be free to enjoy the very special, the

very lovely things... about Holland." The challenge is to be able to enjoy the trip and the sites along the way even though they are different than the ones you originally intended to visit" (Kingsley, 1987). As educators, we perhaps have a unique opportunity as Dutch tour to act guides the above in illustration, helping children reach their full allowing potential and parents enjoy to success their children can achieve in school, but for children with a disability, we must first be aware of their special needs that

should be acknowledged and appropriately addressed.

WEBSITES WITH MORE INFORMATION:

Strokes or other

trauma may cause

dyspraxia ... or it

may be present

from birth.

The Dyspraxia Foundation:

www.dyspraxiafoundation.com

National Center for Learning
Disabilities: www.ncld.org

National Institute for Neurological Disorders:

www.ninds.nih.gov

Childhood Apraxia of Speech Association: www.cec.sped.org



What is Dyspraxia?

The definitions for dyspraxia are varied and numerous, as are the names used to describe the disorder. According to the National Institute of Neurological Disorders and Stroke defines developmental dyspraxia as a disorder characterized by an impairment in the ability to plan and carry out sensory and motor tasks (NINDS, 2006). Furthermore, all of the definitions agree on what dyspraxia is not. It is not a muscle disorder although it involves muscle

coordination and strength. It is not a cognitive disorder although it affects the ability to read, spell and use language. It is a neurological disorder that involves motor planning in all areas of the body when the messages from the brain are unable to communicate directions to the muscles. Velleman describes it "...like

trying to watch cable t.v. stations without the right descrambler. There is nothing wrong with the t.v. station, and nothing wrong with your set. It's just that your set can't read the signal that the station is sending out." (Velleman, 2002).

Dyspraxia may be present in people with autism spectrum disorder, Asperger syndrome and dyslexia. Strokes or other trauma may cause dyspraxia (acquired dyspraxia) or it may be present from birth (developmental dyspraxia).

Other Names for Dyspraxia

Dyspraxia was first described as congenital maladroitness then later as a disorder of sensory integration. Dr. Sasson Gubbay renamed it in 1975 as the 'clumsy child syndrome' but fortunately this name is no longer used. The more current names for

the disorder are:

Childhood Apraxia of Speech (CAS)
Developmental Verbal Dyspraxia (DVD)
Developmental Apraxia of Speech (DAS)
Sensorimotor Dysfunction
Developmental Co-ordination Disorder
Perceptuo- motor Dysfunction
Specific Developmental Disorder of Motor
Function (World Health Organization)

Causes of Dyspraxia

[Dyspraxia is]

an impairment

in the ability to

plan and carry

out sensory and

motor tasks.

There are a multitude of theories as to the cause of dyspraxia, but the answer

remains a mystery. Most would contend that it is a neurological disorder, although this is not documented. Various evaluations have shown these children to have no brain lesions or consistent differences in brain structure. (Hall, 2000). The prevalent theory is that there is subtle brain impairment or malfunctioning.

This impairment may be so slight or so specific that it is impossible to isolate or to determine the cause. Birth or prenatal injuries or oxygen deprivation may have occurred in some cases, however the majority of these children have no remarkable birth history. The bottom line is no one knows the specific cause (Guild & Vail, n.d.).

Who Is Affected?

To be a largely unknown condition, dyspraxia affects a significant number of both children and adults. Barbara Lantin reports "dyspraxia affects up to ten per cent [of the general population], two per cent severely. As with dyslexia, 80 percent of those affected are boys" (Lantin, 1997). If daddy is clumsy or stumbles over speech, watch his sons carefully. Shriberg suggests, "Familial involvement is suspected due to the data



collected on the occurrence in DAS families. Boys are overwhelmingly affected more than girls. The statistics range from a 3:1 ratio to as high as 9:1" (Shriberg, 1997).

Identifying Dyspraxia

Dyspraxia is truly the hidden disorder. Parents who are certain that something is wrong with their child receive virtually no support from the medical and educational communities, and are frequently misled by the word "yet." Typical responses to parental observations of problems with their child include "He's just a late bloomer . . . he's just not crawling/walking/talking yet . . . I wouldn't worry about him yet." The word "yet" implies that waiting is an appropriate action, and whatever the developmental milestone involved is will simply come in time, both deleterious assumptions when dealing with dyspraxia, since early intervention is crucial for children struggling with the developmental and academic issues presented by this disorder. Stordy and Nicholl (2000) reported, "A 1994 survey of 450 members of the Dyspraxia Foundation reported that most parents said they were aware that their child had a problem by age three but, on average, the official diagnosis was not made until the child was six and a half. Only a quarter of dyspraxic children are recognized as having the problem when they start school, and four out of five schools think the child will grow out of it." pediatricians have little experience with dyspraxia, and may simply assure worried moms that their son is just a little behind developmentally. "Many doctors have not yet become fully educated about dyspraxia and are just not aware that it is an acknowledged medical condition" (Stordy & Nicholl, 2000). Concerned parents fare no better when asking schools why their child is having difficulty, since the same 1994 survey revealed, astonishingly, that half of the children's teachers had never even heard of the condition of dyspraxia.

Elijah was diagnosed with DVD at the age of 25 months. His mother and his pediatrician had been watching him closely due to his small head size (microcephaly). The diagnostic tests showed no abnormalities, but he exhibited some of the classic signs of dyspraxia. Around the age of 18 months Elijah began speaking a few words, dada, cookie, cracker, bye-bye. However he lost his ability to use those words and eventually his vocabulary was reduced to "dat"-a one syllable utterance that he used for everything. This circumstance led to a referral to a developmental pediatrician, who then made the diagnosis. At Elijah's six month follow up evaluation, the developmental pediatrician was pleased with his progress. The intensive (3 times a week) speech and occupational therapy is proving to be effective although the progress is slow. At 32 months, Elijah now has a vocabulary of 4 words- a big accomplishment for him. Elijah is fortunate to have been diagnosed and begin therapy at such an early age.

Elijah is now a big brother to Levi. Levi is babbling and meeting his developmental milestones on time, but since dyspraxia runs in families and is prevalent in boys, his parents and doctors will continue to monitor him closely for signs of DVD.

Thus, it is suspected that many children with dyspraxia are erroneously labeled as behavior problems or unwilling

students, simply because their teachers are unfamiliar with the difficulties these children encounter every day (Stordy & Nicholl,



2000).

There are a wide variety of indicators for dyspraxia, but the hallmark of dyspraxic speech development is inconsistency. In infancy, feeding problems may have been apparent, and they make few babbling noises. As a toddler, speech repertoire is limited and they may use one sound or syllable (dat) for multiple meanings. Often children will begin

to acquire speech at a normal time in development, but may regress, losing those words as they get older. Difficulty with speech is directly related to length of the effort; thus, one-syllable words come more easily than multiple syllables, and the child may be

able to say words individually, but sentences are likely unintelligible. A child with dyspraxia frequently appears clumsy and uncoordinated, often bumping into and knocking over people and things. Fine motor skills are extremely difficult and sometimes painful to master. Pedaling and construction toys pose great challenges, and consequently rarely interest the child. Some persons with dyspraxia are overly sensitive to textures and

sounds. Daily tasks such as dressing and tying shoes are typically acquired at a much later age than his peers without disabilities.

To further complicate the detection of dyspraxia, many of these symptoms can be indicators of other developmental delays or

disabilities or may even be present in children with no disabilities. The Dyspraxia Foundation says: "Many parents will say their children have *some* of these problems, but you will know the difference between a normal child with any of these problems and a dyspraxic [emphasis mine]"(Lantin, 1997).

What Can Be Done?

Early diagnosis and intervention is critical. "Fortunately, dyspraxia can be a problem largely confined to childhood as long

as children receive therapy. These children can and do improve, but they do not simply outgrow it without help" (Stordy & Nicholl, 2000). The child's dyspraxic speech will continue to be filled with errors unless s/he receives early, intensive therapy, defined as

direct sessions delivered two or three times a week, for at least two years. Most children who receive intervention can become competent oral communicators (Guild & Vail, n.d.). Occupational therapy in conjunction with speech therapy will improve motor planning skills and speech patterns. The occupational therapist will work to improve daily life skills and coordination problems. Nutritional supplements such as Omega-3

fatty acids and regimens of physical exercise are being studied as possible interventions for dyspraxia, focused on improving brain c o m p o s i t i o n a n d strengthening mental connections (Stordy & Nicholl, 2000).

Having been an early childhood educator for fifteen years, I am guilty of

being one who was ignorant. I would probably still be ignorant and certainly never would have written this article if Elijah had

The hallmark of dyspraxic speech is inconsistency.



If I can stop one heart from breaking, I shall not live in vain;
If I can ease one life the aching,
Or cool one pain,
Or help one fainting robin,
Unto his nest again,
I shall not live in vain.

Emily Dickinson



not come into my life. But now I am aware, and as I walk through the halls of my school and listen to teachers' conversations I cringe as I hear, "he just needs to try harder...if his parents would just work with him...he is lazy...doesn't care ... can't focus...won't try." My grandson's sweet face suddenly appears in front of me and tears well in my eyes. If I heard those words spoken about him, I would be crushed. He is a bright, caring child who tries to communicate in the ways he is able. If I take the time to look into his eyes I can understand what he wants to tell me and his laugh speaks volumes to me. For me, he has put a face on the hidden disability of dyspraxia, and brought into focus the impact teachers can have in the life of a child who faces such developmental and academic challenges.

Most educators want to make a difference in a child's life. However, in order to effectively advocate for the child who struggles in the classroom, we must first educate ourselves about this often overlooked and misunderstood disability that affects a relatively large portion of the school population. Before we disengaged and dismiss a child's abilities, let's examine the possibility of a disability that can be diagnosed and can be treated. What greater legacy could we leave than to empower a person to reach their full potential?

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