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Explaining Learning Disabilities to Your Child

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"Self-knowledge must precede self-advocacy."

—Mel Levine, MD

A parent once called my special education school to request an admissions visit for her and her son, who was struggling mightily in school. She asked a strange question in her initial phone call:

"Does the school have any signs or posters displayed that identify the program as a school for kids with learning disabilities?"

I asked her why she wished to know this.

She replied, "My son doesn't know that he has a learning disability and we don't want him to know."

He knows, Mom. Believe me, he knows.

I have long been puzzled by a parent's reluctance to discuss a child's learning disability diagnosis with him. The knowledge that the child has an identifiable, common, measurable, and treatable condition often comes as great comfort to the youngster. Without this information, the child is likely to come to believe the taunts of his classmates and feel that he indeed is a "dummy." After all, if your child had asthma or diabetes, you would surely explain to her the nature of these maladies and the precautionary steps that she could take to minimize the impact of the condition. So should it be with a diagnosis of learning disorders. The truth will set them free!

If a child does not have a basic understanding of the nature of his learning challenges, it is highly unlikely that he will be able to sustain his motivation in the classroom. Because he is puzzled and confused about the difficulty that he is experiencing at school, he is unlikely to be able to commit himself to his studies. In effect, self-knowledge is a critical step in establishing and maintaining a child's motivation.

When discussing the child's learning problems with her, it is critical to explain what the disorder is—and what it is not. You may find that the child holds many misconceptions about her disorder ("It goes away at middle school"; "It means I'm stupid"; "I'll never be able to read"), and it is important that you clarify and correct this misinformation. Again, if you do not provide the child with accurate information, she is likely to believe the incorrect input that she hears or overhears in the school yard, on the bus, and in the media.

During these discussions, emphasize her strengths and affinities and do not simply focus on her weaknesses and difficulties. Attempt to strike a balance between what she can do and what is difficult for her. Express optimism about her development and her future.

Continually remind the child that she can, indeed, learn but that she learns in a unique way that requires her to work hard and participate in classes and activities that are different from her peers' and siblings'. Emphasize the fact that this situation exists through no fault or choice of the child's. Explain that learning is a particular challenge for her and that it may take her longer to master skills than it will take her classmates. Remind her that she will "finish the race," but it might take her longer and she may have to take a different route. Constantly let her know that the adults in her life are solidly on her side and that she can count on your support and understanding.

It may be helpful to discuss some learning struggles and challenges that you faced during your school years and outline the solutions and strategies that you used at those times. This information can be quite comforting for a child. Although many professionals may disagree with me, I do not find it useful to cite famous people with learning problems as a means of

inspiring and motivating the child. The media is continually reminding us that many notable entertainers, sports figures, entrepreneurs, and politicians have struggled with and "overcome" their learning disabilities. Children with battered self-esteem are unlikely to be inspired by these stories because these youngsters are unable to imagine themselves as successful adults and certainly cannot relate or compare themselves to world-renowned celebrities.

A more realistic approach might be to cite people whom the child knows as inspirational examples: "Did you know that Uncle John also had a lot of trouble in school and he had to repeat third grade? It used to take him forever to do his homework and he still has difficulty writing. But he has a terrific job at the hospital and he is raising a great family. He enjoys cooking—just like you do—and nobody makes a better chili!"

One of the most valuable and important roles that a parent can play in the life of a child with special needs is that of demystifier. The parent should explain the disability to the child, thereby demystifying the child's daily struggles. The youngster often feels greatly relieved once he realizes that his difficulties actually have a name and—most important—that others also have similar problems and challenges.

However, it is important that these explanations be made in a sensitive and age-appropriate way. This important information should not be communicated in one intense "let's discuss your learning disability" session. Rather, you should discuss the child's learning problems with him in a gradual, informal, and sequential way. Many of these discussions will be unplanned and will occur spontaneously in response to incidents that may occur at home or at school. These opportunities for discussion can be an invaluable tool in educating the child about his problems and enhancing his self-esteem. For instance, if the child is having difficulty setting the dinner table and becomes frustrated, you might use that opportunity to explain his sequencing and directionality problems.

"Carl, I know that this is difficult and frustrating for you and I really appreciate your willingness to stick with it. It's tough for you to remember the order you should follow when setting the table, but it will be easier if you refer to the checklist that we made last week. Remember? We keep it on the shelf near the dishes. After you have used the checklist for a while, we will begin phasing it out and I'll bet that you will be able to set the table by yourself within a few weeks. Remember that we followed that process when you learned to make your bed, and you do that chore really well now."

"Remember that the knife and spoon go on the side of the hand that you write with, and the fork goes on the other side."

"These problems that you have relate to something called sequencing and directionality. These skills will always be a little difficult for you, but you are doing much, much better. All of your hard work with Mrs. Carter in your OT class is really paying off. The extra lessons that Coach Simons is giving you in soccer should help your directionality, too."

Often, teachable moments may occur when a child asks a question related to his disability. Remember to answer his questions honestly and sensitively, and be wary of providing more information than the child can understand or handle. As an analogy, imagine that the child is an empty cup devoid of any information about the nature of his disabilities. You are represented by a pitcher, filled with data, reports, information, and knowledge about this disability. Slowly "pour" your knowledge into the cup until the vessel is full. Don't continue pouring until the cup overflows! Put the pitcher down and pour more knowledge into the cup later as it is requested or needed. During these discussions, carefully observe and listen to the child. You will recognize the signals that "his cup is full" and that the discussion should be concluded. Always end the conversation by encouraging him to ask questions, and assure him that you are eager and willing to have these discussions with him.

Of course, the adult should keep in mind the child's age and language skills when having these discussions. A parent-child conversation with a six-year-old is likely quite different from a disability-related conversation with a sixteen-year-old. You may refer to a six-year-old's hyperactivity as "feeling all wiggly"; the adolescent should understand the more clinical

terms of "distractibility," "impulsivity," and "inattention." At times, you may want to compose a simple script before you begin a conversation that may be upsetting or troubling for the child (e.g., about medication, evaluation results, a change in program). Again, it is important that these discussions be open and supportive. They should be conducted in an upbeat, informational, and sensitive way. Always remember that the child's struggles are not his choice—or his fault.

During these conversations, continually remind him that he has a strong and intact support system consisting of adults who truly care about his well-being and his progress. Cite his teacher, grandparents, coaches, neighbors, and extended family. Often, the struggling child feels alone and abandoned. Remind him that he is neither.

When the child is in early elementary school, avoid using jargon or professional terms and use terminology that is readily understandable for her. As she gets older, begin to talk about accommodations and modifications that she may need. ("The teacher will give you more time to finish your test." "Mrs. Chapman has agreed to give you a little less homework than your classmates.") Encourage her to use teacher-pleasing behaviors in response to this extra help (saying please and thank you, making eye contact, being helpful). Reassure her that her negative, fearful feelings are natural and understandable. Emphasize that the child is different, not defective.

This demystification process is a crucial first step in the child's journey toward motivation, independence, and self-advocacy. As an adolescent and adult, she must know how to explain her difficulties and needs to teachers, coaches, supervisors, and employers without parental intervention.