Child Study Center Letter

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Editor's Comment

The *NYU Child Study Center Letter*, published in print format for the last four years, is now published bi-monthly in web format. For your convenience you may download the *Letter* from the web site PDF file so that it will be compatible with all previous issues

This issue of the *Letter* is written by members of the NYU Child Study Center staff. They focus on the importance of communicating in an age-appropriate manner and addressing the concerns of children and adolescents who receive psychiatric diagnosis. Although we refer to Anxiety Disorders, Attention-Deficit/ Hyperactivity Disorder and Learning Disorders, common disorders in children and adolescents, the principles of communication apply to other disorders as well. As parents adjust to the reality of a diagnosis, they may have many emotions and questions, as do their children. Knowledge and sensitivity to the child's perceptions and reactions will enhance discussions between adults and children and contribute to the efficacy of treatment

We thank you for your past interest and hope you will join as a member of our site and continue to read the *Letter* in its new format. For detailed information on the definition, etiology and recommended treatment of the psychiatric disorders highlighted here as well as other diagnoses, visit the Mental Health section on this site.

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TALKING WITH KIDS ABOUT ADHD, ANXIETY AND LEARNING DISORDERS

Introduction

Despite the great amount of information available to parents about the diagnosis and treatment of child and adolescent mental disorders, there are few resources available to help parents and other adults respond to the questions and concerns of the children themselves. When children don't have accurate and specific information, they often construct their own interpretation and misconceptions may arise.

The child with a Learning Disorder may think: *I'm stupid; I'll never learn; there's something wrong with my brain.*

The child with an Attention-Deficit/ Hyperactivity Disorder may think: *It's like I can't stop myself; sometimes a twister hits me.*

The child with an Anxiety Disorder may think: *I won't know what to say at the party and people will look at my pimples, so I better stay home.*

When parents confront the possibility that their child may have a mental disorder, they begin a process of inquiry which ultimately leads to a diagnosis and plan for appropriate treatment. Along the way parents grapple with questions such as: who's responsible, what is the illness, why did it happen, where did it come from, how can we fix it? Parents can be flooded with thoughts and emotions upon hearing their child has a problem such as an Anxiety Disorder, a Learning Disorder or an Attention-Deficit/Hyperactivity Disorder, the most common disorders of childhood and adolescence. One useful way for parents to cope with feeling overwhelmed by the unknown is to search for answers. Just as importantly, children need answers to the very same questions as their parents. With knowledge comes confidence, a sense of control and optimism in being able to successfully meet a challenge. Surprisingly, for both parent and child, awareness of a diagnosis can bring relief rather than guilt or shame as they learn together about the nature and treatment of the disorder.

Although there is no one right time or one right conversation to have with the child who receives a diagnosis, some general principles can serve as a guide. In the context of an age-appropriate discussion, the child can be helped to learn useful factual information about what her diagnosis means and how it is treated.

Adapt your explanation to the age of the child

Very young children are concrete in their thinking; they handle information best when it is given to them in short, simple facts related to their immediate world. They live in the moment and lack the ability to deal with concepts relating to the distant future. Therefore, it's helpful to talk about things in terms of a specific time, from event to event - for example, saying "we'll try this until your next birthday" has more meaning than "we don't know the long-term side effects of this medication." Young children have a self-centered view of the world and may think the problem is their fault or that they are bad. By the age of 8 or 9, children want and can understand specific facts and information. They are interested in more sophisticated and technical explanations. By adolescence youngsters can deal with abstract issues such as understanding the long-term aspects of the illness and the part the illness plays in the establishment of their individual identity. Parents should also address issues of self-image and how the disorder and treatment affect peer relationships.

Start from the child's perspective

Get the child's point of view. Ask him what he notices about the problem. It can be helpful to refer to behaviors or incidents as examples of the child's difficulties, such as trouble finishing homework, continual interrupting at home or in school, avoidance of parties. While it may be tempting to repeat the doctor's words or terminology, it is vital that you serve as interpreter. At some point, however, use the actual terms of the diagnosis, since information should come directly from parents. Although the explanation of the condition is certainly more important than the clinical term, using the actual term will help to demystify it and prepare the child for understanding the term when he eventually hears others use it.

Have more than one conversation

Talking about a diagnosis should be an ongoing series of discussions, not just a single information-giving session. Parents should be prepared with information and have answers ready, even if the honest answer is "we don't know." Children need time to hear what is said, they process information differently as they grow older, and they must feel comfortable coming to their parents with questions.

Practice telling others

Role-playing questions and answers can help clarify the child's understanding and also helps the child anticipate questions and reactions from friends, family members, and teachers. By thinking ahead to situations your child might encounter and by practicing possible answers, the child will feel more confident in dealing with questions. Both parents and child must determine their own level of comfort with disclosure. They must decide how much they want others to know and even who they want to tell about the problem. We like to think we live in an era of acceptance and that children can be the standard bearers for acknowledging who they are and dispelling stereotypes about mental illness. This is a personal decision and one that may change in the course of the child's lifetime.

Enlist help

Parents need not be solely on their own with the initial disclosure of a diagnosis to their child. They can ask for advice from the mental health professional who participated in assessment of the problem and knows their child, and perhaps they can all meet to go over the information together.

Plan for treatment

Parents should focus on the fact that the child can be helped. They should be aware of possible treatments and give the child choices about treatment options whenever possible. The more the child feels included, the more likely she is to cooperate.

Resources

Once parents are aware of a specific diagnosis, they will find books, parent and child groups and other sources of information about the problem. Parents can look for further opportunities to discuss the disorder when the subject arises, perhaps when watching a television program in which a character portrays someone with similar behaviors and feelings.

Specific guidelines

The guidelines above are general. In the following sections on Anxiety Disorders, Learning Disorders and Attention-Deficit/Hyperactivity Disorders each author will discuss

- the professional view of the disorder
- how to explain assessment, diagnosis and treatment to children
- issues relevant to the specific disorder

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TALKING WITH KIDS ABOUT ANXIETY DISORDERS

What is an anxiety disorder? The professional view

Anxiety is a normal emotion experienced by individuals of all ages. Anxiety can be extremely useful, propelling the autonomic nervous system's "fight or flight response," which helps one avoid dangerous situations. In children and adolescents, certain anxieties are normal and developmentally appropriate. For example, it is appropriate for a child to be nervous about starting school and to get tearful when saying goodbye to a parent on the first day. However, when a youngster experiences excessive fear or worry which interferes with his functioning in school, at home, or with friends, the reaction is no longer within normal limits.

The anxiety disorders which affect children and adolescents are Separation Anxiety Disorder, Generalized Anxiety Disorder, Social Phobia, Panic Disorder with or without Agoraphobia, Obsessive Compulsive Disorder, Specific Phobias, and Posttraumatic Stress Disorder.

Anxiety disorders are among the most common mental health problems in childhood. Some children and adolescents are more predisposed to anxiety than others. Certain of these youngsters may experience a life stressor that prompts an inappropriate anxiety reaction while others may experience anxiety problems as a result of the confluence of their own biology and life experiences. Regardless of the initial cause of the anxiety, it is highly treatable; more than 90% of individuals treated for anxiety recover fully.

How to explain an anxiety disorder to kids

Explaining the assessment

When you and your child see a professional for an assessment of anxiety you will most likely be asked a lot of questions about your child's development, history, and her reactions in a variety of situations in school, with friends, and at home. In addition, you and your child's teacher may be asked to fill out questionnaires. The professional you see may also want to observe your child in school or with peers. A specific type of assessment procedure, the behavioral test, is often used in cases of anxiety. Behavioral tests may involve testing your child's reaction to and tolerance of situations. For example, a child who is fearful of the dark may be asked to try and sit in a darkened room. Behavioral tests yield important information about your child's baseline anxiety level. During the assessment process you and your child may be seen individually or together. All professionals are different so when you make an appointment, specifically ask what the evaluation will entail and approximately how long it will last so you and your child can be prepared.

Explaining the diagnosis and treatment

First, start the discussion knowing the child's point of view. If your child feels that she has been having difficulties in school, with friends, or at home, you can use these concerns as a starting place for your discussion. If she has not voiced any concerns, you can describe some of your observations. For example, "*I know you get really shy around other kids sometimes and that makes it hard to do things like give book reports and write on the board in school. We want to see a doctor who will help you feel more comfortable doing some of these things.*"

Be honest with your child. Tell him your specific concerns and how and why you think this professional can help. Tell your child you know that sometimes anxiety makes certain situations difficult for him. Assure him that he can learn to control that anxiety.

Answer whatever questions your child has, whenever they arise. Remember, you and your child are probably learning about anxiety and its treatment together so it's okay if you don't have answers to all of your child's questions. If you don't know the answer, tell him you don't know, but that you will ask the doctor and let him know the response.

When the assessment process has been completed and a diagnosis assigned, treatment recommendations will be made. Two specific modalities for the treatment of anxiety are medication and Cognitive Behavior Therapy, used alone or in combination. Medications are available which work directly on the central nervous system and brain to calm a youngster and re-set his anxiety threshold. Cognitive Behavior Therapy (CBT), in individual or group sessions, is very effective in assisting a youngster with controlling his anxiety. CBT involves education about the nature of anxiety and teaches specific skills for managing the physical sensations, negative thoughts and problematic behaviors that accompany anxiety disorders. Through CBT a youngster learns to systematically master the situations that cause the anxiety. The youngster will most likely be given assignments to work on at home to supplement the work being done in the sessions. Parents may also be asked to participate at home.

Conclusion

Parents can best help their child by providing him with accurate information about what to expect, an environment in which he can ask questions about the disorder and its treatment, and reassurance that he can learn to control the anxiety and return to a normal life.

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References

Eisen, A. R. & Kearney, C. A. (1995) *Practitioner's Guide to Treating Fear and Anxiety in Children and Adolescents: A Cognitive-Behavioral Approach*. Northvale, N. J.: Jason Aronson, Inc.

Labellarte, M. J., Ginsburg, G. S., Walkup, J. T., & Riddle, M. A. (1999) The Treatment of Anxiety Disorders in Children and Adolescents. *Biological Psychiatry*, 46:1567-157.

TALKING WITH KIDS ABOUT ATTENTION-DEFICIT/ HYPERACTIVITY DISORDER (ADHD)

What is an attention deficit/hyperactivity disorder? The professional view

ADHD is a brain-based disorder described by professionals as a group of behaviors that occur when self-control is not developed appropriately in relation to the child's age. Typically, but not always, the child with ADHD has a history of difficulties well before he gets to school. By the time the child enters group or school-type settings, parents begin to get consistent feedback about difficulties with attention, impulse control, or high activity level which intrudes on learning and social functioning.

The term ADHD encompasses three subtypes:

a) **Predominantly inattentive type** - characterized by symptoms of inattention, distractibility and disorganization. Children with these symptoms often make careless mistakes, lose things necessary for school or activities, and often procrastinate or fail to complete their work.

b) **Predominantly hyperactive-impulsive type** - characterized by fidgetiness, motor restlessness, and inability to wait one's turn. Children with these symptoms often blurt out answers, cannot wait in line or take turns and have trouble remaining seated.

c) **Combined type** - characterized by symptoms of both of the above subtypes.

How to explain ADHD to kids

Explaining the assessment

Unfortunately, children (and their parents) learn very early on that things are not going well, and fear that they may be at fault. Prior knowledge about the assessment process can alleviate anxiety and enhance active participation for both parent and child. Information is obtained by means of face-to-face interview, standardized questionnaires, and sometimes direct observation in school.

Explaining the diagnosis and treatment

The job of both parents and professionals is to present information about ADHD in a way that helps children feel they can understand their behavior and learn strategies to control it. Remember that the explanation should be expanded over time as the child progresses through developmental stages. As ADHD is a condition that usually exists throughout life, it is important to help the child understand that he will need to learn to live with it and adjust over time.

It is often useful to use metaphors in talking about ADHD. For children with hyperactivity and impulsivity, many people use the comparison to a car whose motor revs up too fast and whose brakes don't seem to work as well. For children with just inattention issues, comparison to television sets with five stations on all at once often works well. Be mindful that overly technical references about synapses, neurotransmitters, PET scans, and other discussions overly focused on the brain, although truly reflective of the state of the science, can be interpreted by younger children as meaning they have faulty brains or brain damage. Be on the lookout for these misinterpretations.

Work with the child at his own pace. Remember that some children receiving the diagnosis need to go through stages that can include shock, anger and denial before they can move into more productive stages of self-care. Try and seize the proverbial "teachable moment" - the time when something happens that the child wishes he could change - to continue discussions about diagnosis and treatment.

Dr. Russell Barkley, an eminent researcher on ADHD, advises parents to keep the "disability perspective" in mind – to remember that they are dealing with a child with a problem, that the child is not the **cause** of trouble, but is **in** trouble.

In discussions with the child, it is helpful to focus on what the child has said he is concerned or frustrated about. For example:

You know those times you wish you could have focused more on homework so you had more TV time at night?

You know those times you wished you were included more on the playground?

Notice the emphasis on striving for the positive, desired behaviors rather than on the negative, undesired behaviors. Children are apt to feel defensive, deflated and pessimistic if talking about their new diagnosis is simply a rehashing of how frustrating life can be.

Research data and clinical experience support the combined use of medication and behavior therapy. When discussing treatment, realize that the terms *deficit*, *hyperactivity* and *disorder* are all emotionally loaded words with charged meanings that children don't usually find comforting. In discussing the aims of treatment, emphasize positive goals such as:

Working together to stay on task so you have more free time.

Learning how to get in control when you're angry so you can have the privileges you enjoy so much.

Becoming more organized so you can keep up with other kids.

Treatment should be described as a method that can help the child be more in control, rather than letting the ADHD be in control. Teens are especially sensitive to the issue of someone trying to control them. Resistance to medication should be respected and worked through, not enforced simply based on parental authority.

Provide incentives that are meaningful to the child and motivate him to

increase the desired behavior. Avoid goals such as "get into trouble less" which sound negative. Track positive behaviors with your child, day by day, to help you all see if treatment is working and how.

Since ADHD tends to run in families, parents who also have ADHD have a wonderful opportunity to show their child how to deal with ADHD. They can model appropriate expression of feelings about having ADHD and perhaps view it as an opportunity and a challenge rather than as a handicap.

Parents can model how to look at and accept one's own strengths and weaknesses, showing their children how they embrace their weaker, problematic traits and celebrate their strengths.

Conclusion

The goals of talking about ADHD to youngsters are to:

- Find a way to help them understand their behavior but to also protect their often fragile self-worth, restore their hope and optimism and encourage them to actively participate in their own care over the long run.
- Enable them to incorporate the disorder into their sense of self and, for older children, to understand that it will play a role over the life span.
- Help the child understand ADHD so that the explanation leads to action, rather than to an excuse that holds the child back.

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Recommended Books

Quinn, Patricia and Stern, Judith. (1991) *Putting on the Brakes*. Magination Press (8-13 year-olds).

Galvin, Matthew. (1988) *Otto Learns About His Medicine*. Magination Press. (4-8 year-olds).

Dendy, Chris. (1995) *Teenagers with ADHD*. Woodbine House.

TALKING WITH KIDS ABOUT LEARNING DISORDERS

What is a learning disorder? The professional view

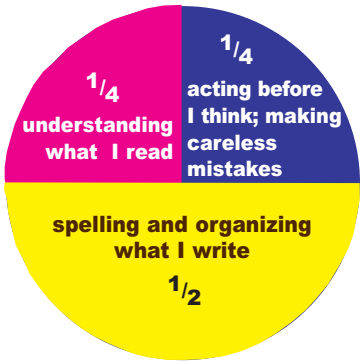
A learning disorder is a neurological disorder that interferes with a person's ability to store, process or produce information and creates a "gap" between one's ability and performance. Individuals with learning disorders are generally of average or above average intelligence. Learning disorders can become apparent in different ways. Some children have difficulty with handwriting or putting their ideas into written form. Other children have difficulty reading, following directions, completing math problems or understanding or using language. For some children their difficulties affect only a small portion of their school life, but for others all schoolwork is a struggle. Individuals with learning disorders can have marked difficulties on certain types of tasks while excelling at others. Learning disorders are not cured and do not go away, but individuals can learn to compensate for and even overcome areas of weakness.

How to explain a learning disorder to kids

Explaining the assessment

Parents are interviewed to gather the child's developmental, educational, social and family histories. The time allotted and the types of tests to be administered; e.g., tests of intelligence, memory, coordination, processing, achievement should be made clear. Since children with learning problems often feel that they aren't smart, they are apt to be anxious about the assessment process. Telling the child what to expect and explaining that he can't fail the tests helps alleviate the worry for parents and kids.

Some professionals begin assessment by collaborating with the parents and child in understanding the process. For example, in a technique developed by Marcia Stern, Ph.D., a psychologist and collaborator with the Unique Minds Project of the Ackerman Institute for the Family, the parents and child create "A Piece of the Pie." Parents and child list the aspects of learning and together they decide which aspects cause the largest problems in school. They create a pie picture by assigning a ratio number to the different problematic aspects of learning, and finally the different pie pieces are colored in. One example:



The completed chart can be a helpful and concrete tool for many children and serves several purposes. First, the family can refer to the chart when explaining to the child why she is about to be tested and what they hope to find out. The chart is also a handy reference when the testing is completed. It enables the family to explain further what caused them to initiate the evaluation and to reflect on whether the results confirm the child's initial perceptions.

Explaining the diagnosis and treatment

Telling a child about her learning strengths and weaknesses often relieves worry and pressure. A child can be reassured to hear there is a reason for her problems. An informing session is generally held after the assessment with a professional who may meet with the family together or meet with the child briefly beforehand so that the child feels he is in charge of the information that will be discussed. Many adolescents prefer time alone with the professional to discuss information that may have been told in confidence. In most instances a child's self-esteem is enhanced during the evaluation and feedback process, as the examiner delineates strengths with specific examples from the testing process.

The child should be assured that he worked well and told directly if the work he did highlighted a specific area of difficulty that impacts on his work. At this point referring back to the "pie

chart" can be helpful. The child should be given many opportunities to ask questions and should be assured that he can improve. Specific methods of how this can be done should be described.

Explanations should be continued over a period of time at home between child and parents, with subsequent consultations with the professional when desired. Parents (and professionals) should remember to adjust their language to the age of the child. For example, rather than saying that a learning problem is a neurological disorder, they might say that brains are wired in different ways and people need to learn in different ways.

Many children worry about talking about their learning differences to their friends. The family can help by role-playing some possible explanations, as follows:

Age 4 to 6: *I go to a special helper.*
I go to a teacher who teaches me special learning tricks.
It's hard for me to know letters, just like some things are hard for you.

Ages 7 to 9: *I'm good at math, but Mrs. K. helps me spell.*
Mr. Z. helps me remember things.
Letters don't look clear to me so Mrs. K. helps me figure out new words.

Ages l0 to 12: *I need new techniques for reading because I learn differently.*
I' m getting extra help to do better on tests.
It's hard for me to write things down, but I can talk out my ideas.
I have to read something a few times so I can remember it.
I have trouble with book reports so my coach helps me plan my time and figure out what to do first.

Conclusion

The goals of talking about learning disorders with youngsters are to:

- Enable them to understand the nature of their difficulty and alleviate the guilt that they may be responsible.
- Help them appreciate their strengths and understand that people have different modes of learning.
- Enlist their cooperation in the recommended methods of treatment and help them recognize that professionals know how to help kids with learning disorders manage, learn and grow.

Author: Susan J. Schwartz, M. A., Ed., is the Clinical Coordinator of the Institute for Learning and Academic Achievement at the NYU Child Study Center with special interests in phonemic awareness as it relates to reading acquisition and in study and organizational skills.

Recommended Books

Levine, Mel. (1990) *Keeping A Head in School: A Student's Book about Learning Abilities and Learning Disorders*. MA: Educators Publishing Service.

Levine, Mel. (1993) *All Kinds of Minds: A Young Student's Book about Learning Abilities and Learning Disorders*. MA: Educators Publishing Service.

Stern, Marcia (1999) *Unique Minds Program for Children with Learning Disabilities and Their Families*. Unique Minds Foundations, Inc.

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