

What Do Parents of Children with Learning Disabilities, ADHD, and Related Disorders Deal With?

Family Matters

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Children with learning disabilities, attention deficit/hyperactivity disorder (ADHD), and related disorders puzzle parents because of their many abilities and disabilities. It can also be difficult to understand how much of their behavior is the nature of the condition and how much is oppositional. It is all too easy for parents to "catch" a child's feelings of inadequacy and then feel bad as a parent. Parenting approaches that include clear, concise instructions; structure without rigidity; nurturing a child's gifts and interests; and constant approval of positive behavior help parents feel better and help children feel safe. It takes time for both children and parents to embrace the concept that being different does not mean being inferior and, in fact, can be a good thing. Parents need to be nurtured and praised to help them nurture and praise their children. Most parents use almost every resource they have to help their children flourish, and still, they worry they are not doing a good enough job. Usually they are!

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Few people realize how difficult it is to be a parent... until they become a parent. Parents are totally responsible for the safety, welfare, and education of a tiny infant who quickly becomes a growing, ever-changing, maturing child. Parents have to set their own rules, develop their own routines, and form their own expectations. When parents are married, differences of opinions have to be worked out with the greater good of the child held aloft. If it is difficult to be a parent, it is even more difficult to be a parent of a child with special needs.

Discovering a child's special needs is often a confusing and painful process for parents. First of all, because learning difficulties can be subtle, multiple, and difficult to pinpoint, it can be hard for parents to know whether things are normal or not. Especially with a first child, parents may not know when to expect vocalizing, playing with sounds, and learning to speak. It is also difficult to distinguish between a healthy, very active toddler and a hyperactive toddler with ADHD. What is the difference between the child who is a little clumsy (which he will outgrow) and a child having significant motor skills problems? What are the indications of the child being off course in his ability to listen and follow directions? It may take some time for parents to recognize and articulate concerns.

Even after a diagnosis, parents often face a whole gamut of emotions before they can grapple effectively with the stark truth that their child has learning disabilities. Parents may move through emotions like Kubler Ross' (1980) stages of grief, initially denying there is a problem and rationalizing why it's not a problem, then having to deal with the fear, the anger, and the guilt of having a child who experiences many difficulties. It is normal for parents to want to blame somebody - anybody - and to bargain in the sense of thinking

been follows, and finally parents can come to accept the child's strengths and weaknesses and try to figure out a helpful plan of action (Kubler-Ross, 1980; Smith, 1995).

Neurologic Basis

Parents often feel guilty because they feel their child's learning disabilities, ADHD, and related disorders are somehow their fault. But, that is not true. Parents may tend to feel that if they had been stricter, demanded more, forced more practice, it would have changed the situation. That would not have changed the situation.

Children and adults with learning disabilities often have clusters of difficulties that lead to academic failure or low achievement. These disabilities emanate from a neuro-physiological base: It is as though the switchboard of the brain short circuits some of the information coming in, scrambles it, and then loose wires interfere with the ability to get that information out. This neurological dysfunction contributes to disorder, disorganization, and problems with communication. Parents can be reassured that these problems are organic and are not caused by external factors (Smith, 1991; 1995).

For years there have been nay-sayers who claim that there is no such thing as learning disabilities - that there are lazy children and motivated students, that there are stupid children and bright students. However, technological advances over the last 5-10 years have laid those issues to rest. Brain researchers using multiple resonance imaging (MRI) have shown differences between the brains of individuals with learning disabilities and those without (Dr. Martha Donckla, personal communication). Researchers have also found images of ADHD in the central nervous system (Dr. Xavier Castellanos, personal communication). The architecture of the brain of the child with learning disabilities is different.

Brain researchers also point out that neuronal links in the brain typically travel in particular patterns, but in individuals with learning disabilities, they are scattershot all over the brain, resulting in unusual linkages (Dr. Gordon Sherman, quoted in *The Doctor is In*, 1988). Consequently, exceptional disabilities are often linked with exceptional abilities. As an example, for over 35 years, graduates of the Lab School of Washington have become very successful in the arts as graphic artists, film makers, fashion designers, jewelry makers, actors, architects, photographers, musicians, dancers, and computer graphic specialists. A number of the graduates have also become highly successful entrepreneurs and business executives. Parents can take reassurance in the fact that many *abilities* usually accompany the constellation of problems or cluster of difficulties that constitute learning disabilities.

Understanding Behaviors

It is often confusing to parent children with learning disabilities, ADHD, and related disorders. One of the biggest confusions and challenges parents face is the large hiatus between what the children *can do* and what they *cannot do*. Often they are very smart, know a great deal, and reason well, yet cannot read or write. School teachers and family may be telling them to try harder, and they are usually trying their hearts out. They tend to work 10 times harder than

Another aspect of the confusion for parents lies in how hard it can be to distinguish between a child who *can't* do something and a child who *won't* do something. For parents, it can be vexing not to be able to control a 5 or 6-year-old or to know whether to push an adolescent or reduce expectations. In this confusion, parents tend to ask, "What is wrong with me?" rather than "What challenges is my child having to face?" Shifting this focus can be therapeutic for parents and children.

Children may seem to be having behavior problems when, in fact, they are confronting difficulties in accomplishing a task. Children tend to withdraw or act out when a task is too demanding. It can help parents to know that when children say they hate something, that usually serves as a wonderful diagnostic tool, indicating what is difficult or impossible for them. For example, when a child loves dance, art, and music but hates drama, it could be that the child has a speech/language problem. When a child hates math or reading, these are likely areas of difficulty. Conversely, what children like and want to do usually serve as indicators of their strengths.

While a diagnosis will help to some extent, the job of sorting out these issues on a day-to-day basis is no small task. On a planning level, confusion occurs because teachers, doctors, psychologists, and social workers may disagree not only on diagnosis but on the best treatments or programs for a child. This can be frustrating and anxiety-provoking for parents who have to pull all the information together and decide what to do, right or wrong. Additionally, at home and elsewhere, parents must anticipate problems and sense when their children are tired, or frustrated, or about to explode. Parents must trust their guts as to how long the child can last at a party, or sit in a restaurant, or be pleasant with visitors. While parents have to do this with all children, it is much more challenging with this population.

Parents of children with special needs are constantly trying to puzzle out what's working, what's not working, what causes the child frustration, and what brings the child pleasure. Parents have to analyze everything, think carefully, reflect on activities of each day, and problem-solve to recognize the children's strengths, interests, and areas of difficulty, and come up with plans for managing the child's behavior and supporting the child's development. ~

The Family with the Child with Special Needs

Learning disabilities can be hard on a family. One parent, often the mother, may recognize and face the problem sooner or more readily than the other. Misunderstanding and conflict can result. Brothers and sisters often resent the amount of attention given to a child with special needs and may proclaim knowingly that the child is "a spoiled brat" who is perfectly capable. Grandparents tend to blame parents for not

doing enough, not being disciplined enough, organized enough, or not giving enough direct help to the child. Neighbors can be intolerant if the child is very hyperactive or has low frustration tolerance and tends to explode or cry at each hurdle.

On a daily basis, children with special needs typically raise the irritant factor in family life. They tend to leave everyone on edge because their behavior is unpredictable, erratic, inconsistent, and full of ups-and-downs. Children with learning disabilities and ADHD are usually very disorganized. They have trouble dealing with sequences and order, so they don't plan well. They are distracted easily and often impulsive. Just getting washed and dressed in the morning can be an arduous task, sometimes resulting in explosions on the part of the children, their parents, or both. Clashes frequently emanate from a child's misunderstanding of instructions or going off on a tangent. To complicate the problem, when wrong or criticized, children with learning disabilities tend to fall apart, withdraw into day dreaming, or strike out in one form or another.

Emotionally this population is very immature and fragile. These children tend to personalize things that have nothing to do with them. For example, when family members are laughing at something, children with special needs are often convinced that they are being laughed at, and, as a result, they get very upset. Furthermore, their moods swing widely, and a child may be laughing one moment, crying the next (Smith, 1995). This emotional lability is hard to live with. Children with learning disabilities and ADHD are prone to depression (Smith, 1991). Their sense of defeat and failure is contagious and, sometimes, the whole family feels their helplessness and despair. Often adults, otherwise incredibly competent in their daily lives, feel incredibly incompetent when with these children. This can take a toll on parents, and support and education may be necessary to bolster parents' sense of confidence and competence in effectively parenting the child with learning disabilities.

Parenting Strategies

Addressing difficulties with time and space. Space and time are organizing systems involved in every task, every performance, every aspect of life. Yet, because of central nervous system dysfunction, neural immaturity that tends to disorder, and poor organization, many children with learning disabilities are very disorganized - unable to keep their rooms anything but a complete mess, unable to accomplish even the simplest task in a timely fashion, unable to follow instructions, likely to lose belongings frequently, and appearing lost in time and space. Problems with sequencing explain why they have trouble remembering the days of the week, seasons, the alphabet, counting, and the order of

tasks and instructions. These problems are why they have trouble beginning projects, sustaining them, and finishing them. Poor organization not only affects home life and relationships with friends, who will take only a certain amount of forgetting and lateness, but also academic life. Poor organization means forgetting to bring home the homework or not having the time management skills to meet deadlines. It affects being able to establish priorities - what is most important to study, what is less so. Often this disorganized behavior looks oppositional and hostile, when actually it stems from the very nature of the learning disability.

Parents and teachers of children with learning disabilities can help them by providing clear structuring of time and space. To help children with structuring space, visual aids can be useful. For example, shelves can be used instead of drawers so children can see where things belong and how to put them back. The use of other visual cues, such as lists or labels, can augment efforts to help children organize tasks and belongings.

Developing understandable and reinforced routines can help with structuring time. Breaking routines and other tasks into manageable chunks and communicating what must be done first, next, and last is important. A large number of children with learning disabilities have language learning disabilities, which means they have trouble deciphering language, listening, and following instructions. Because of this, it is also helpful if parents and teachers limit the number of words used in giving directions, using simple phrases such as, "Go upstairs. Close the window. Come down."

Parents can also assist their children by engaging them in planning activities. Examples include planning celebrations, planning a garden, organizing what needs to be done to collect food for the homeless, or any other kind of planning that involves developing lists, going shopping, checking off the lists, and then charting the tasks still to be done (which can then in turn be checked off). All of these projects are useful, engaging, and have the hidden agenda of working on organization skills.

Addressing relationship difficulties. While learning disabled children face challenges academically, a problem that many parents find more troubling than difficulties with the 3 R's (reading, writing, 'rithmetic) is the 4th R: relationships. Many children with learning disabilities cannot play successfully with even one child and certainly not two. They don't read social signals - facial expressions, gestures, or tones of voice any more than they read letters or words. Additionally, many of these children are literal and concrete, they can not deal with subtleties, nuances, inferences, or multiple meanings. This affects family life and peer relationships because they often can not understand jokes, subtle teasing, or sarcasm. One of the consequences of this is that they have to be taught explicitly how to relate to others. Parents have to work with them on "reading" faces, "reading" gestures and movements, and learning what is and is not appropriate to say. Parents may have to coach them through common social situations until they develop appropriate interpersonal behaviors.

Parents can provide their children with practice in anticipating what might happen in various social situations. They can role-play with their children about what to do or say when they want to join a game that their cousins or friends are playing, or when grandparents say, "Read this to me." Some parents have found it useful to show the wrong way of handling a situation and then to have their children critique them. The process of acting situations out, problem solving, and talking about the situations, helps many children with learning disabilities and ADHD think through various options.

Promoting self-esteem. Early on, children with learning disabilities begin to notice that others can do easily tasks that are intensely difficult for them, and they begin to feel bad about themselves. They may receive frequent criticism or, at best, global praise such as "You are doing better" (better than what?), "You are doing fine" (what is fine?), "You are making progress" (what is progress?). Criticism damages self-esteem, and global praise is often too abstract to be meaningful to concrete thinkers.

By training themselves to comment on the positive as much as possible, by offering concrete comments on what their child is doing well, and by using very specific praise, parents will cultivate desired behaviors and boost their children's self-esteem (Smith, 2001). Examples of specific praise include phrases such as: "You finished the assignment," "You are listening carefully," "You are sitting properly and looking at me," "You remembered to bring home the work you have to do," "You cleaned the table after dinner," "You picked up the bag the lady dropped. Thank you." With specific praise, a child can be very clear on what behaviors are liked and expected.

Visual, concrete proof of progress also helps children notice and feel confident about their progress and accomplishments. Home made certificates, gold stars, stickers, charts, and check lists with lots of checks can be used when children work hard on tasks at home, such as remembering to take out the garbage, shopping without forgetting, setting the table correctly, making their beds, and putting the toilet paper into the holder when the last piece has gone.

Parents and teachers also boost a child's self-esteem by seeking out what he or she can do well and fostering and supporting these areas to the hilt. Whether it is an art form, science, nature, photography, computer work, selling things, inventing, or telling stories, children with learning disabilities need parental support to become "the best" in this area at home and to bring their talent into school. It won't help them feel better about their academic performance, but it will help them feel better about themselves.

Teaching children that many people have overcome difficulties to become successful is another valuable parenting strategy. One way to do this is to read or play tapes of biographies in which children or adults have had to struggle to achieve their goals - adventures where the characters got lost or had to fight sharks or other beasts; stories of achieving despite illness or disability; or stories of fighting prejudice or unfairness. Children enjoy and benefit from discussing these kinds of challenges. Additionally, when parents can introduce their children to highly effective members of society who struggle with disabilities, particularly disabilities similar to those the child faces, children can hold their heads higher. All members of society who are functioning well with learning disabilities and ADHD - firemen, policemen, plumbers, day care center workers, business executives, park rangers, recreation coaches, athletes, and celebrities can serve as role models and inspiration for children with learning disabilities.

When parents learn to cherish diversity, their children learn there are many different ways to celebrate birthdays, get married, raise children, and so forth (Smith, 1994). These children feel better about themselves when they understand that doing things differently, learning differently, being different is OK, and that differences can enrich our lives. Artist Chuck Close said, "I think accomplishment is figuring out your own idiosyncratic solutions. Accomplishment is being able to do what you want to do even if you don't do it the way everybody else does it" (Smith, 1991, p. 103, and personal communication).

Empowerment. Children with learning disabilities and

ADHD often feel powerless and inadequate. They tend to be passive learners and need to be totally involved in activities to make them active learners. Parents can encourage hands-on activities, such as cooking, cleaning, shopping, and running errands to show children that they can make things happen. These learning activities have the additional benefit of resulting in tangible, visible products appreciated by the whole family.

Parents must beware of doing too much for children with learning disabilities because that does not empower them. The effects of active engagement are in fact neurological. California neurobiologist Marion Diamond's research (Diamond & Hopson, 1998) shows that the sights and sounds of enriched environments cause dendrites to form neural pathways that she calls "magic trees of the mind." Her data demonstrate that the curious mind, stimulated to further inquiry, makes the central cortex thicker, activating the brain to further enhance learning (Smith, 1995).

Parents can also empower their children to view obstacles as challenges and to know that they have a lot going for them and a team behind them. It helps children with learning disabilities when parents can adopt a problem-solving mode rather than always providing the answers. It helps to say, "What can we do about this?" "What options do we have?" "Let's figure out where we can find the information we need" instead of doling out the right answer much of the time. Parenting children with learning disabilities and ADHD demands enormous problem-solving, and on top of that, parents need to help turn their children into outstanding problem-solvers. Grappling with adversity, figuring out strategies that work for them, and learning when to ask for help and who to ask are crucial life skills that these children must learn and will hold them in good stead.

Parents can foster curiosity in their children and lay the framework for thinking and questioning. When children's minds are questioning everything, their bodies are active, and their hands are into things, children are helped to achieve the highest cognitive development possible. Parents work with their children to develop critical thinking skills when they have them look at photos or drawings and piece together what could be going on; when the family watches a TV show and the children are asked what the big message was; when a mystery story has been read and the children guess who did it; or when a family plays games like chess, checkers, Clue®, and Stratego™. Children often can teach their parents how to work computers, and programs like HyperStudio® allow children to draw, to photograph, to speak, to scan objects from the Internet, and to make rewarding, satisfying multimedia presentations that simultaneously use and develop many skills.

Cultivating Parental Optimism

Because it can be frustrating to parent children with learning disabilities and behavioral challenges, it is encouraging for parents to know that some of the "negative" behaviors of their children very often become positive attributes in adulthood. For example, the most stubborn children often turn out to have fierce determination. The most manipulative children often turn out to be fabulous entrepreneurs, leaders, or politicians. The children who argue all the time like jail house lawyers actually become lawyers, and those who doodle and draw all through school may well become artists in adulthood. In 35 years of experience at the Lab School in Washington, DC, this pattern has been evidenced again and again. The boy who sold his mother's jewelry for 25 cents apiece grew up to be a real estate mogul. The boys who were "tinkerers," taking everything apart, became mechanical engineers. The girl who tried to help her

classmates avoid arguing, who was teased because she was always trying to make peace and never projected any opinion of her own, became a mediator - and a good one at that! Numbers of very hyperactive youngsters have turned out to be very energetic, productive entrepreneurs. The inflexible "one way" kids have often become scientists who study one problem in depth for many years or airplane controllers who focus intensely on the task at hand. Many bright children with ADHD, who were impulsive, very distractible, and had poor attention spans, have grown up to be outstanding emergency health care specialists, paramedics, and firemen. In an emergency, their adrenaline is apparently stimulated, so they become highly focused, able to put their excellent analytic abilities to use while doing many tasks.

Self-care should be a priority for parents of children with learning disabilities. Parents themselves need nurturing to help nurture their child with special needs. They need to go out and have fun regularly. They need more sleep than other parents, for these children sap their energy, and their condition demands help from parents constantly. Finding supportive friends or relatives, or locating a support group or an on-line parent support community can provide a place for parents to vent frustrations and obtain valuable suggestions, strategies, and support. Laughter is also important for parents and the whole family. Children with learning disabilities and ADHD need to feel that it is not the end of the world that they have these disabilities - nuisances - and they need to laugh at some of the nonsense they go through. Parents, too, need lightness and humor. When parents can have fun with their children - even being silly and laughing - and can enjoy life as much as possible together, everyone benefits.

It is hard to be a grown up, difficult to be a parent, even more challenging to be a parent of a child with special needs when the parent must become the analyst, the interpreter, the problem solver, the cheerleader, the lawyer, the psychiatrist, the spiritual advisor, the organizer, the notetaker, the friend, companion, advocate, and disciplinarian. Most parents use every resource they have to help their child flourish, and yet, they worry they are not doing enough or a good enough job. Chances are parents are doing an incredibly fine job under difficult circumstances. Professionals need to realize and appreciate the heavy load carried by parents of children with learning disabilities, ADHD, and other related disorders.

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