

Parents -- Their Child's Home Information Specialist

It is common to hear parents talk about feeling intimidated by all of the professionals who participate in planning meetings for their child. I know I have felt that way on more than one occasion. It really helped to boost my confidence when I realized that I actually have important information about my son.

I know things that others do not. I am aware of the ways he responds to people who come into our home. Although his multiple disabilities have profound impacts on him physically and mentally, it is heart-warming to watch him respond to friends and family members who speak "his language." That's why a sign in his room reads, Love Spoken Here.

His dad and I also know that he often gets upset when our discussions turn into arguments. We refer to this as his "emotional radar." It really kicks in whenever someone new begins working as his care provider. He makes sure they have what it takes to do the job successfully.

As his parents, we are more aware of how he is affected by his surroundings. We recognize his intolerance for certain noise levels --frequency and/or volume. We also see how lighting affects his comfort, especially if it is florescent, flashing or shining directly into his eyes. We know that his body can be warm on one side and cold on the other, and how quickly he can overheat, becoming wet with sweat and clammy to the touch.

You are also a specialist who has unique understanding about your child! In addition to your observations, you have instinctive insights because of the parent-child bond you share. Even if your child has completely different challenges from mine, your special knowledge can be extremely valuable whenever you meet with a teacher, doctor, therapist or a team of professionals.

If you want a title, call yourself a Home Information Specialist. I have seen parents carry totes printed with that designation at conferences and to parent or team meetings.

Always remember, you are an expert on your child!!!

Some food for thought:

IDEA, the Individuals with Disabilities Education Act, made it possible for all children with disabilities to attend school. The law told public schools that they needed to provide a free, appropriate, public education (FAPE). It is known as an entitlement program.

When it comes to adult services, programs have various eligibility requirements. In some cases, people who are eligible end up on waiting lists since there is no law requiring services for adults with disabilities.

Every parent of a child receiving special education services needs to know about the difference between eligibility and entitlement. Then we will understand better why we should study and learn what it will mean for the future of our adult children.

Questions for Parents so Young Children Learn Independence:

1. What choices do I let my child make?
2. What things do I do for my child that he/she could be learning to do for him/herself?
3. What opportunities do I provide for my child to try new things?
4. What does my child learn from me about coping with, and learning from, my mistakes?
5. How can I learn to let my child take reasonable risks so he/she can become more responsible?
6. What daily living skills am I teaching my child?

Childhood and Adolescent Depression

Depression in children and teens was one topic at a conference last November. The workshop was presented by Dr. L. Read Sulik, Medical Director of Child and Adolescent Psychiatry at St. Cloud Hospital. Many children and adolescents are referred to him because of behavior problems. When they are described as “mad all the time,” by others or themselves, he suspects depression until proven otherwise.

Mood changes are expected in the teen years. But when teens experience extreme sadness, irritability or mood swings, depression may be the cause. Dr. Sulik describes them as “living without joy.” Their mood changes, they lose interest, withdraw socially, become more isolated and experience boredom.

Sleep difficulty and fatigue are physical symptoms he sees in teens with depression. They may have trouble getting to sleep or awakening during the night or early morning. Sleep deprivation can lead them to appear “spacey.” And it is not unusual for them to be fidgety from fighting off fatigue. This may also contribute to their craving for carbohydrates.

Distorted thinking affects them, and they may worry even though they do not realize it. Difficulty concentrating, decreased attention and focus, increased

distractibility or daydreaming may also be seen. Some may be troubled by morbid or suicidal thoughts.

Dr. Sulik's approach to depression involves treating it and managing it. Treatment may include medication, therapy (individual, group, family), and/or hospitalization. Therapy aims to: improve the teen's self-awareness; develop self control; learn relaxation skills; recognize signs of depression; and be able to live a healthy lifestyle.

Education is used to reduce or eliminate fears, and teens become "experts" on depression. (Educating families of depressed children has similar benefits.) Education leads to greater understanding of depression and is the basis for learning how to manage it. Managing depression includes a set of healthy lifestyle choices and family support and respite if needed.

Promoting Mentally & Emotionally Healthy Teens

A Research Brief, written and distributed by Child Trends reviewed nearly 300 research studies on teens' mental health and emotional well-being. They looked at programs and approaches that had been evaluated experimentally to identify "what works." They also reported on "best bets" that need further study to verify their value. They considered two categories of mental health disorders:

Internalizing disorders like depression, anxiety and eating disorders, reflecting a troubled emotional state within the person and
Externalizing disorders such as conduct disorder, attention-deficit hyperactivity (ADHD) and alcohol and drug abuse that are expressed more openly.

If you want to read about their findings, visit their website, www.childtrends.org. If you do not have a computer, ask your public librarian to locate and print off the Research Brief. Or you can request the information from the Windmill Project.

Healthy lifestyle includes: nutritious diet, adequate sleep, exercise, relaxation, proper use of meds, follow through with therapy, chemically free, support system in place, play or have fun, and spiritual dimension.

Derek's Miracle Is Having Fun

Speech, physical and/or occupational therapy, doctor's visits, surgeries--not much fun for the children who need them. And when activities like youth soccer, t-ball, bike riding or roller-blading are impossible, parents want to find a FUN activity for their children to do. Well, what about horse riding for a boy who spends most of his time in a wheelchair?

-more-

Derek has Cerebral Palsy with very low muscle tone. He can't sit or stand by himself so he depends a lot on his wheelchair. His doctor, Paul Bergstrand, mentioned a therapeutic riding program to his parents. Sharon Bridges, a physical therapist at the Osakis public school where Derek goes, told his mom that she thought Derek might benefit from riding. Sharon is actively involved with Miracle Horse Riders, Inc. In addition to serving on its Board, she evaluates new riders to make sure they can participate safely.

Janel (Derek's mom) met and talked with a representative of MHRI. She viewed parts of their video and visited with another mom whose child was riding. She left that day with an application and physician's permission form. When he started riding, Janel said "he couldn't hold his head up; he was like a limp noodle."

Derek has been riding once a week, weather permitting, for three years. He is stronger, has better head control and is more coordinated. Equally, or even more important, is how much Derek enjoys the time he spends riding. He shows his excitement by babbling and kicking his feet when the car turns toward the arena. It is the special thing he does that his siblings don't get to do. His parents gladly pay the \$15 each week and pray that someday MHRI will have a climate-controlled arena so Derek and others can ride all year long. Janel wants other parents to know, "This has been the best thing for us to do."

Riders from 3 to 89 years old have participated. Those with physical injuries, like a badly broken leg, as well as a wide range of disabilities have benefited. Some have Cerebral Palsy, like Derek; others have autism or generalized developmental disabilities. It has also been effective for some children with severe emotional or behavioral disorders.

MHRI makes its program available to as many people as possible by keeping the cost to riders down. This labor of love depends on many hours donated by dedicated volunteers and caring people who began and maintain the program.

- MHRI has an indoor arena near Urbank in southeast Otter Tail County of Minnesota. For specific details call Candy (218-267-5216).
- Seventeen programs in Minnesota are listed at www.narha.org along with one in Fargo. A new program in Pope County is underway; call Lorna (320-239-2670).
- If a child receives county social services, it may be possible to have riding written into the annual plan. Discuss it with your child's case manager.