

HYDROCEPHALUS

▪ ASSOCIATION ▪

SUPPORT EDUCATION ADVOCACY

A
TEACHER'S
GUIDE
TO
HYDROCEPHALUS

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“Hydrocephalus,” by J. M. Fletcher, et al., in K. O. Yeates, et al., *Pediatric Neuropsychology: Research, Theory, and Practice* (New York: Guilford Press, 1999)
National Information Center for Children and Youth with Disabilities, www.nichcy.com
Nonverbal Learning Disorders on the Web, www.nldontheweb.com
“Nonverbal Learning Disorders,” by Sue Thompson, M.A., LD Online, www.ldonline.org
“Nonverbal Learning Disorder Syndrome,” Fact Sheet, Hydrocephalus Association
“Social Skills Development in Children with Hydrocephalus,” Fact Sheet, Hydrocephalus Association
Special Education Rights and Responsibilities, Community Alliance for Special Education (CASE) and Protection and Advocacy, Inc. (PAI)
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Foreword

This booklet about hydrocephalus is written for teachers in the hope that the information will give you a better understanding of this lifelong condition and how it can affect a student's ability to learn and mature intellectually, socially and emotionally.

As a teacher, you are not just an educator—you are a role model, a mentor and a guide. Having a student with hydrocephalus in your class can be a challenge, but it also presents a special opportunity. Most children with hydrocephalus have normal or above-average intelligence and are eager and willing to learn and succeed. It is not uncommon, however, for them to have learning disabilities that have the potential to hinder their overall development if not recognized and remediated in a timely matter.

Hydrocephalus affects about one in every 500 to 1,000 children born. It is caused by a wide variety of medical problems, and the circumstances of each child's condition are unique. There is no standard profile of "the child with hydrocephalus"—just as there is no standard profile of "the typical child."

We will discuss some of the common challenges faced by many children with hydrocephalus, but it is important to remember that some children will face more serious challenges, while others will have far fewer problems. A discussion of more severely affected children and their special-education needs is beyond the scope of this booklet, which primarily discusses the needs and challenges of children in mainstream classrooms.

We hope that this booklet will give you a better insight into how hydrocephalus can affect a child's learning style and social and emotional growth; provide you with strategies to recognize and help remediate areas of weakness and vulnerability; and empower you to challenge all of your students, especially those with special needs, to fulfill their potential.

Introduction

Hydrocephalus is sometimes referred to as an “invisible disability”—meaning that the disability is not immediately visually apparent. Many people with hydrocephalus look “normal.” Underneath a seemingly typical exterior, however, there lies a host of potential physical, emotional and intellectual problems. The most common of these are learning disabilities, poorly developed social skills and some degree of loss of fine or gross motor skills.

Many children with hydrocephalus have undergone traumatic experiences, often at a very young age: multiple surgeries, frequent hospital stays, lengthy rehabilitation and countless doctor visits and medical tests. Starting school for the first time or returning to school after a hospital stay can be an extra challenge. It can be scary not just for the child with hydrocephalus but also for his or her peers, who often do not know how to express their own fears and concerns. This in turn can result in peer rejection, loneliness and isolation.

Children with hydrocephalus are often characterized as bright and highly verbal. They often have a lot to say and are friendly toward their teachers. And yet this very sociability and intelligence can mask some deeper problems. Though they may be very verbal, their conversation may have little depth or lack sophistication. They may befriend adults and children younger than they are. Often, they do not possess the same nuanced social skills as their peers.

Their parents and teachers may be blinded by displays of verbal intelligence, especially in the younger grades, not realizing that learning disabilities often do not become apparent until later on, in the middle grades. Sometimes, what appear to be behavioral issues can be manifestations of learning disabilities. A student who appears to be not applying him- or herself, or simply not trying, may in fact be struggling very hard to keep up. Yet it’s not simply a matter of working harder or studying more: it’s a matter of learning *how* to work and study in order to learn and retain knowledge and skills.

Children with hydrocephalus are always at risk—of recurring medical problems, new or changing learning disabilities, and social and emotional issues. As their bodies change and their minds develop, new physical, psychological and neurological issues may arise. They may develop more, not fewer, problems in school. Any changes in their skills, capabili-

How to Read This Booklet

Throughout the book, we use quotes from children with hydrocephalus, their parents and their teachers.

There are also sidebars to point you to further information on a particular subject, or to an appendix in this booklet.

“Andrew was evaluated for learning disabilities when he was very young, around kindergarten. He had an IEP, but then went on to perform ‘too well’ to continue to qualify for special services.

When he started having trouble again in the fifth grade, we were all caught by surprise.”

ties and emotional makeup must therefore be assessed in light of their hydrocephalus.

But with early intervention and remediation, many of these difficulties can be minimized. Early testing is crucial, as are periodic follow-ups and ongoing evaluation. A host of well-established strategies can be put into place, including physical/occupational therapy to improve coordination and motor skills, resource classes to improve study skills and tailored learning strategies to combat learning disabilities.

Children who have always done well in school—so well, in fact, that they may never have had an IEP or neuropsychological testing—are perhaps most at risk, as the warning signs may not be picked up as quickly. Still other children with hydrocephalus will face far greater obstacles and require a higher level of interventional assistance.

As a whole, children with hydrocephalus are eager and willing to learn and grow—but they are often frustrated by their troubles in keeping up with their peers and pleasing their teachers and parents. With your help, they can achieve great success.

What Is Hydrocephalus?

Hydrocephalus is the abnormal accumulation of cerebrospinal fluid (CSF) within cavities called ventricles inside the brain. CSF is produced in the ventricles, circulates through the ventricular system and is absorbed into the bloodstream. Hydrocephalus occurs when there is an imbalance between the amount of CSF that is produced and the rate at which it is absorbed. As the CSF builds up, it causes the ventricles to enlarge and pressure inside the head to increase.

What Causes Hydrocephalus?

Hydrocephalus can be present at birth (congenital) or acquired at any time during a person's life as a result of hemorrhage, meningitis, head trauma, tumors or cysts. Congenital hydrocephalus frequently occurs in association with other conditions, such as spina bifida or Dandy Walker syndrome.

How Is It Treated?

The most common treatment for hydrocephalus is a surgical procedure, performed by a neurosurgeon, in which a tube called a shunt is placed into the child's body. The shunt channels the flow of fluid away from the brain or spinal cord into another part of the body, where the fluid can be absorbed and transported to the bloodstream. This reduces pressure on the brain, which could, if left untreated, result in permanent brain damage or death.

Shunts are extremely durable, and rarely fail or malfunction due to external causes such as falls or bumps. Almost all children with hydrocephalus can and should participate fully in all school activities, including physical education and sports.

However, because shunts are mechanical devices, they sometimes malfunction and, less frequently, become infected—in fact, most people who have shunts will require shunt revision at some point in their lives. A concise list of signs and symptoms of a shunt malfunction or infection appears in Appendix C.

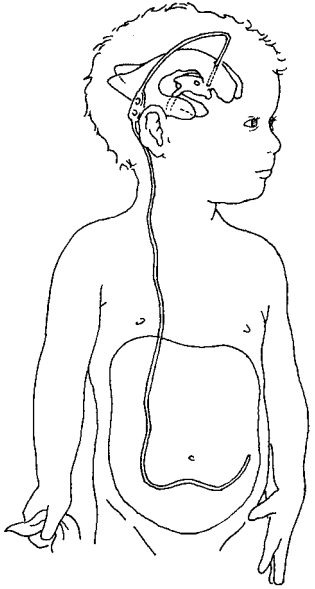
If you would like a more in-depth description of hydrocephalus and associated conditions, ask your student's parents for a copy of our booklet *About Hydrocephalus—A Book for Families*. Also see Appendix D for a list of additional resources.

See Appendix B for a statement about participation in sports from the Hydrocephalus Association's medical advisory board.

Third Ventriculostomy

While shunting is by far the most common treatment for hydrocephalus, a new procedure called endoscopic third ventriculostomy (ETV) is gaining popularity. The surgery involves making a tiny hole in the third ventricle of the brain to allow the flow of spinal fluid into another area of the brain for absorption, thus eliminating the need for a shunt.

However, long-term success rates of ETV are still unknown, and as with shunted hydrocephalus, complications can arise at any time. We at the Hydrocephalus Association strongly encourage children with hydrocephalus who have had ETVs to carry a medical ID card identifying them as having non-shunted hydrocephalus.



This drawing depicts a child with a ventriculo-peritoneal (VP) shunt, which drains the excess cerebrospinal fluid from the brain into the abdomen.

*Image reprinted from
About Hydrocephalus—
A Book for Parents.*

What Are the Effects of Hydrocephalus?

Pressure on the brain can result in short- or long-term effects, including impaired vision, headaches, hearing loss, muscle weakness, seizure disorders and hormonal imbalances. Chapter 2, “Physical Problems,” discusses these in greater detail.

Another related effect of hydrocephalus is the possibility of learning disabilities. These are covered in detail in Chapter 3.

Conclusion

Hydrocephalus is a lifelong condition, for which there is no cure. Nonetheless, with advances in medical treatment, children with hydrocephalus are growing up to live long, full lives. They may still face many obstacles, including learning disabilities, other medical problems and impaired social skills development, but with help from all of us, they can triumph physically, intellectually and emotionally.

Physical Problems Associated with Hydrocephalus

Hydrocephalus is often accompanied by other medical conditions, such as spina bifida, Dandy Walker syndrome and cerebral palsy. If your student has one of these conditions, you will probably already know about it from their IEP (individualized education plan).

Many children with hydrocephalus receive interventional services in preschool and early grades, to work on their coordination and motor skills. Many also receive physical and occupational therapy throughout their school years. Information about these interventional services can be found in the student's resource file. Communication between teachers and therapists/resource specialists is key to the child's success.

Ideally, all children with hydrocephalus should undergo comprehensive developmental testing at a young age. A neuropsychological evaluation by an experienced neuropsychologist is extremely important, both for assessment and for developing strategies. Any significant results from these tests should be included in the child's IEP. Follow-up testing should be conducted periodically to assess any changes. Any relevant results and information should be stored in the student's resource file and discussed during his or her IEP.

Shunt Revisions

Most children with shunted hydrocephalus will undergo at least one shunt revision in their lifetime. Some children have numerous revisions, sometimes several in one year.

When a child returns to school after a shunt revision, she will have an incision on her head and/or behind her ear, an abdominal incision or, in fewer cases, an incision over the heart. Usually a patch of the child's hair will be shaved, near where the incision was made, and the sutures may be visible. Some children prefer to wear a cap to cover this area, and the child's preferences should be observed in this regard.

Vision Problems

High cerebrospinal fluid (CSF) pressure can damage vision. Visual problems vary from a subtle mild visual deterioration to a marked loss of vision. Some children develop eye misalign-

IEPs are covered in greater depth in Appendix A.

See Appendix C for signs and symptoms of a shunt malfunction.

“When Aaron went back to school after his first shunt operation, you could see his sutures—and the outline of his shunt—through the shaved spot on his head. It was all very visible, and a little daunting to see. We thought for sure he would want to wear a cap to hide the bald spot and sutures, but Aaron said it was too itchy and that he didn't care if people saw his scar—he'd just tell them he had surgery, and that was that.”

“Going through puberty early was upsetting to Ashley. She was embarrassed and uncomfortable around her peers. It was a difficult time for the whole family. We kept reassuring her that what she was going through was normal and that soon the other girls would be having the same experience. Keeping the lines of communication open was important.”

Some children with hydrocephalus experience chronic headaches. Many have found that one way to ease the pain is to lie down for a short while—this eases the pressure on the brain and helps the child relax.

Physical therapy needn't just be of a formal nature. Participation in “regular” sports or dance helps develop coordination, motor skills and social skills—and is fun, too.

ments (strabismus) that can force them to assume an uncomfortable head posture with a tilt or turn. Sometimes eye muscle surgery is offered to improve eye alignment.

Vision problems may also affect perceptual abilities, as well as hand/eye coordination.

Precocious Puberty

It is not known for certain why some children with spina bifida or hydrocephalus go through precocious (premature) puberty. It is thought that the alteration to the brain anatomy associated with hydrocephalus somehow affects the pituitary gland. Children with central nervous system (CNS) disorders, brain tumors, meningitis and trauma are also more likely to have an early onset of puberty. Precocious puberty may lead to age-inappropriate behavior, which can add additional stress to the situation.

Headaches

Children (and adults) with hydrocephalus have headaches, just like everyone else. Sometimes, though, headaches can be so severe as to interfere with a student's ability to concentrate. Severe and recurrent headaches can be a sign of shunt malfunction and should be taken very seriously.

Seizures

A small but significant percentage of children with hydrocephalus have seizures. The exact link between hydrocephalus and seizures is not known. Sometimes medication is necessary to control or prevent seizures, which may lead to its own side effects. If a child is on anti-seizure medication, this information should be explained in the IEP and communicated to his or her teachers.

Hand/Eye Coordination

Children with hydrocephalus frequently have poor hand/eye coordination and fine-motor skills, which is most often reflected in poor handwriting. Physical or occupational therapy may be recommended to help develop these skills. Such therapy is most effective when it is initiated at an early age.

Learning Disabilities

It is not uncommon for children with hydrocephalus to have some degree of learning disability. Those most often associated with hydrocephalus are:

- Nonverbal learning disorder
- Difficulties understanding complex and abstract concepts
- Difficulties in retrieving stored information
- Spatial/perceptual disorders

Sometimes problems are apparent at a very young age, but often they do not arise until about the third or fourth grade, when learning becomes complex and abstract, rather than concrete.

All children with hydrocephalus should have an IEP, which outlines problem areas and sets in place strategies for overcoming them. However, for a variety of reasons, some children are not identified for testing and intervention, and thus do not have IEPs in place. We cannot emphasize strongly enough the importance of early intervention in infancy or preschool, if possible.

When they know what to look for, teachers can be sensitive to the possibility of learning disabilities and, with a general understanding of children's changing academic capacities, can anticipate in which grades children may encounter greater problems.

Children with hydrocephalus are likely to have learning disabilities in specific information-processing areas. As they grow older, it is likely that they will improve less in certain language skills compared to their peers—thus, problems may emerge in the fourth grade that were not evident in the third, and so on.

Students can often be in denial of their special needs and unwilling to ask for help—and sometimes parents, too, can be in denial of their child's needs.

As we've mentioned repeatedly in this booklet, each child is unique. Just because many children with hydrocephalus have learning disabilities, it does not follow that every child has them. It is important, however, to be aware of the potential for problems, while expecting the most of each child.

“A student who has innate difficulties reading, spelling, and/or expressing herself stands out in most classroom situations. And likewise, a student who is a top reader, achieves excellent spelling scores, and expresses herself articulately usually does not prompt her teacher to consider a learning disorder. But, this is often exactly the presentation a child with NLD syndrome manifests in the early elementary grades.”

(Sue Thompson, MA., "Nonverbal Learning Disorders," 1996)

“Gerard was a straight-A student and a voracious reader. But when he hit the sixth grade, reading wasn’t fun for him anymore—it started to be a chore. As the reading materials became more sophisticated, he had trouble keeping up with his classmates. He could still devour sports novels in hours, but when asked to analyze a more age-appropriate novel and give his perspective on the characters and themes, he really struggled.”

“Our son was struggling with note-taking in his high-school classes. We came up with what we thought was a brilliant solution: He could tape-record his classes and then have a complete set of ‘notes’ to refer back to. As it turned out, though, it simply meant that he had to sit through each class two or more times, as each night he struggled to transcribe every single class.”

Nonverbal Learning Disorder

People with nonverbal learning disorders (NLD) do not accurately process information that is not verbal or linguistic in nature. Instead, they rely almost exclusively on a very literal interpretation of verbal communication. Their ability to organize the visual-spatial field, adapt to new or novel situations and/or accurately read nonverbal signals and clues (such as body language) is impaired.

Children with NLD often appear to do well in their early elementary years, except when their fine-motor difficulties get in the way, or they fail to attend to a math symbol calling for addition or subtraction, or some other subtle symptom of their disorder derails them.

As they enter the upper elementary grades or begin middle school, they are left to handle more tasks on their own. Things rapidly begin to deteriorate. They may get lost, forget to do homework, seem unprepared for class, have difficulty following directions, struggle with math, be unable to comprehend their social studies textbook, have trouble writing an essay, continually misunderstand both their teachers and their peers, and often be anxious in public and angry at home.

These behaviors result from the child’s struggles, but are often misunderstood and labeled as bad behavior. Some characteristics of NLD are similar to, and often misdiagnosed as, attention deficit hyperactivity disorder (ADHD).

Students with NLD generally appear to possess above-average cognitive skills because of their verbal strengths, but often show academic difficulties as they reach the middle-school years. Thus, they may be quick to learn to read and pronounce words fluently in early grades, but they may have greater difficulty deriving meaning from the text.

NLD encompasses three categories of dysfunction: motor (lack of coordination, balance problems and difficulties with fine grapho-motor skills); visual-spatial-organizational (poor visual recall, faulty spatial perceptions, difficulties with spatial relations); and social (inability to comprehend nonverbal communication, difficulties adjusting to novel situations and deficits in social judgment and interaction).

Many children with hydrocephalus, whether or not they are diagnosed with NLD, have deficits in these same areas. Thus, the discussion that follows encompasses both NLD specifically, and the challenges faced by children with hydrocephalus more generally.

It is important to note that not all children with hydrocephalus have NLD, but that they may still face challenges in one or more of these areas.

Motor Skills

Some children with hydrocephalus have poor psycho-motor coordination, which is often manifested in clumsiness and a

general unawareness of the space their bodies occupy. These children seem to be constantly “getting in the way.”

Fine-Motor Skills

Their fine-motor skills are also affected, creating difficulty with printing and cursive writing, cutting with scissors, tracing, artwork and participating in games. Handwriting may be unevenly spaced, the quality poor and execution very slow, with limited production. Computer use should be encouraged for all writing assignments—some school districts may even provide laptop computers for home use.

Visual Motor Skills

Children with hydrocephalus may have difficulty judging distance and direction or seeing and organizing a sequence of movements or events. They may also have trouble separating relevant information from a background, such as one figure in a picture of several items. This may affect their ability to interpret meaning from pictures, keep within lines when coloring or find their place on a page.

Spatial orientation—the ability to assess size, distance, direction, position or quantity—may also be impaired. They may have problems differentiating left from right, over and under, backward and forward.

Organizational Skills

Whether or not they are diagnosed with NLD, many children with hydrocephalus have problems with organizational skills. For example, they may have difficulty following instructions with more than one step. The neatness and quality of their work may be affected. They may require additional structure in the classroom and at home.

Children with hydrocephalus (and/or NLD) often have trouble integrating and interpreting incoming information. They tend to pay attention to each detail as it comes in, rather than combining them into more meaningful wholes. The effort quickly leads to information overload. Some students try to cope by clinging to familiar habits and routines that help them to structure their world. Sometimes this means of coping appears as misbehavior, laziness or inattentiveness, when in fact the opposite is true.

Teachers can support students with organization difficulties by outlining material to be covered; using overheads containing central points while lecturing; providing clear schedules of the day's events; breaking down complex tasks into smaller, sequenced pieces; using discussion rather than lectures to develop and integrate ideas; and using students' strengths in rote learning to help them develop habits and routines to organize themselves and their work. More strategies will be discussed at the end of the chapter.

“For the past three years, Robert has submitted almost all his homework by computer. He types in his answers and emails the file to his teacher. This way, his work is neat, and can be completed in a realistic timeframe.”

“Instead of using a binder, Jane uses an expandable file folder for her notes, handouts and assignments. She has separate pockets for assignments, handouts and in-progress homework. When she finishes an assignment, she files it away in the ‘done’ folder. No more loose sheets of paper fluttering out of her binder!”

“Both of my daughters have hydrocephalus, and both consistently test in the 98th percentile on standardized tests for math and sciences. Elizabeth is majoring in electrical engineering, with a secondary degree in mathematics. Both my daughters needed lots of help in English and writing, but I don’t attribute that to their hydrocephalus. Their little brother is also poor at English, and also not so good at math, but he doesn’t have a shunt—just a 16-year-old smart mouth.”

“Lee loves math, but he works more slowly, and completing homework assignments can take him a very long time. So instead of requiring him to complete all ten problems in a homework assignment, his math teacher allows Lee to do, say, five of the problems—which demonstrates his understanding but doesn’t monopolize his evening.”

Memory

Impressive rote memory skills can fool teachers and adults into thinking that the child understands more than he or she does. Children with learning problems can often recite lengthy tracts but, if questioned on the content, may be unable to explain the meaning or answer questions about what they have memorized.

Math

Many—but certainly not all—children with hydrocephalus have difficulty with math. For those who do have problems with math, they generally are able to grasp the basic concepts but are stumped by the practice—fine-motor skills, sequencing and rote tasks. For example, a child who knows her numbers and understands the principles behind multiplication may not be able to recite the multiplication tables.

For some students, higher abstract math, like algebra, may be impossible. In such cases, the academic program may need to be modified.

Attention

Some children with hydrocephalus and/or NLD have trouble paying attention in class. They are sometimes labeled as lazy, dreamy, unmotivated or inattentive—but in fact their behavior means they are trying to stay on track/stay focused, or they have gotten lost in the instructions or complex language (e.g., too many commands given at once).

Verbal Abilities

Hypervocal communication—also called “cocktail party syndrome”—is often found in children with hydrocephalus. The child never seems to stop talking, yet content, if analyzed, is usually superficial or even inappropriate to the situation. Cocktail party syndrome can fool those who don’t realize that the chatter is often meaningless; it can also mask some real learning disabilities in listening or understanding the relevant aspects of a situation.

Strategies

Early identification is the most important tool for overcoming learning disabilities. In the best-case scenario, the child with hydrocephalus will have undergone comprehensive evaluation by an experienced neuropsychologist, preferably in the preschool years. In reality, however, many children receive only adequate to insufficient evaluation from a tester who is not experienced with hydrocephalus or with the more complex issues involved. Baseline as well as follow-up testing are crucial for children with hydrocephalus.

Task analysis—breaking an activity into smaller, achievable steps—is an excellent strategy. Using strengths (especially verbal) and allowing alternate means of expression (such as a tape-recorder or a computer) can be very helpful. Motivation is also key.

Teachers can:

- Be sure to have the child's attention before telling or showing him or her something.
- Give short assignments that can be done successfully.
- Use schedules and lists wherever possible.
- Provide an extra set of books for use at home.
- Allow verbal reporting as an acceptable alternative to writing.
- Provide additional time to complete timed tasks such as tests and assignments.
- Provide a separate room for taking exams, away from distractions.
- Decrease the required quantity of written work.
- Break down tasks and instructions into small, clear steps.
- Allow the use of calculators for math problems and tests.
- Allow the student to use a computer and email for homework assignments.
- Communicate with parents early and frequently.

With their teachers' help, students can:

- Obtain a set of notes from the teacher, or have a peer make a copy of their notes.
- Use a timer or a watch with an alarm.
- Reduce clutter in work area.
- Position desk close to the blackboard or where distractions are reduced.
- Use a homework book, organizer or notebook to keep track of homework assignments.
- Use graph paper for math assignments, to keep columns aligned and numbers organized.

Social and Emotional Issues

For most of us, happiness means friends—the move from isolation to inclusion. It means comfort with social interaction so that other people are motivated to actively seek us out, or at least not ignore us. The acquisition of social skills is critical for social inclusion.

Children with disabilities can feel socially isolated and rejected. This can be particularly true when, due to their specific learning disabilities, they have been unable to develop social skills appropriate to their age. This social isolation and frustration at not fitting in or feeling different can in turn lead to emotional problems.

Not every child with hydrocephalus experiences these problems, but it is important to be aware of the possibility.

Social Skills

Most social learning is done automatically, by seeing, copying and conditioning. Social skills are usually learned incidentally, without formal instruction. However, many children with hydrocephalus may have learning problems that make it difficult or nearly impossible to pick up the verbal and nonverbal cues necessary for the acquisition of social skills.

Children with poor social skills often have difficulty processing nonverbal and spatial information. As a result, they frequently misinterpret subtle social cues like facial expressions, gestures and tones of voice.

The often invisible nature of hydrocephalus can also mask the subtle traits that accompany it. For instance, many children with hydrocephalus are very verbal, but often their conversation has little depth. They can appear immature, as they are often slow to process information from their peers. Subtleties of expression or social decorum are not always understood. They may gravitate toward children younger than they are, who are not as socially mature as their own peers.

Intonation

Children who have trouble with nonverbal cues often have difficulty perceiving intonation. They translate statements quite literally. For example, a phrase like “nice going” means something different when you’ve just dropped a ball or tripped over

Extracurricular activities, particularly in junior high and high school, can be a great way for students to make friends. A perceptive teacher might notice a student’s interest in the environment and recommend that she join the ecology club. Joining clubs not only creates a community of potential friends for a child, it also gives him or her something to do at lunchtime, when he or she might otherwise be sitting and eating alone.

“Our son refused to admit that he needed any help with schoolwork or with social situations. Instead, he withdrew, becoming quite angry and anxious over little things. Finally, we got him to see a psychiatrist, and it turned out he was severely depressed.”

“For several years, Ramon has mentored and tutored kids in the special education class in his high school. Some of these kids are pretty severely affected. Helping them out gives Ramon an incredible sense of pride and self-worth.”

“Annie loves babies and young children. She is also very outgoing and friendly with adults. But Annie has no friends who are close to her own age. The ‘rules’ of her peer group—including what or who is cool or ‘in’—are too complicated, and change too quickly, for her to keep up with them.”

a skipping rope than when you’ve gotten a perfect score on a spelling test. The child hears the words but not the tone. Errors such as these can be incredibly painful for kids who are not attuned to nuances in tone, pitch or rhythm.

Hidden meanings have to be pointed out. The child has no way to access what is “meant” but not actually said.

Posture and Facial Expressions

If a child can’t read faces very well, he or she will likely interpret things incorrectly. Often, children with hydrocephalus perceive only two kinds of facial expressions: “happy” and “mad” (and perhaps a third, “sad”).

Distance and Spatial Relationships

Children with hydrocephalus also frequently mis-estimate distance and spatial relationships; they get too close to other people (getting in their face) or they stay too far back. Getting too close causes others to back off and find an excuse to escape, while staying too far back makes eye contact difficult and is likely to cause others to ignore them.

Social Cues

Children may also have difficulty picking up other social cues, such as those from clothing, for example. Someone dressed in a suit and carrying a briefcase tells us, “I am an authority.” If a child doesn’t pick up such cues, he or she might not figure out who is the authority or boss.

These deficits in social awareness and judgment are often misinterpreted as “annoying” or “attention getting” by adults and children alike. Although these children are struggling to fit in, they continually commit blunders, hence the label “annoying.”

Emotional Issues

Children with poor social skills are likely to have fewer friends and greater difficulty interacting with peers, leading to a sense of social isolation and emotional turbulence. It has been noted that children with NLD are especially inclined toward developing depression and/or anxiety disorders. And children with physical disabilities are already aware of their difference from other children. Absences from school due to illness or medical treatment only compound this isolation.

Children with hydrocephalus have learning difficulties that affect them in all areas, not just one subject, such as math. This can lead to social isolation, which children will sometimes try to alleviate by interacting only with adults, who are more appreciative of their verbal strengths and less concerned about physical awkwardness or violations of social conventions.

An inevitable result of isolation is anger. For some children with hydrocephalus, this anger results in violent outbursts that

may seem irrational and frightening. Similarly, it is not uncommon for children with NLD to be misdiagnosed with attention deficit disorder or emotional disturbance.

Other children may retreat into depression, convinced that there is little hope that their situation will improve.

Strategies

It is extremely important for the social and emotional issues simply to be acknowledged. They can then be better defined through testing and included in the child's IEP.

Early intervention is absolutely crucial. Even if a child does more or less catch up with her peers, it will probably happen over time and some skills may always be missing. The first step is a neuropsychological evaluation by an experienced neuropsychologist, which can pinpoint areas of deficiency and identify the necessary strategies.

Teachers can:

- Assume you have to tell the child everything—he or she cannot simply observe and learn.
- Verbally teach strategies for conversation, such as give and take, beginnings and endings of a conversation, how and when to change the subject, formal versus informal speech and tone of voice.
- Verbally teach strategies for assessing body language (facial expressions, correct social distance, etc.).
- Talk through situations in order to give the child a verbal view of someone else's internal speech process. Help the child develop a sequence of steps for self-monitoring, verbalizing each step.
- Verbally point out distinctions between appropriate and inappropriate behavior; group the child with good role models.

Practice Makes Perfect

Parents and teachers can help children with hydrocephalus learn more effective social skills by talking about social rules and playing games in which children guess the feelings that go with facial expressions and tones of voice, and figure out appropriate responses.

For some children, it may help to write out scenes describing new—or even everyday—social interactions, so that they can learn what is expected of them. In rehearsing these scenarios, they can also learn what kinds of phrases and emotional responses are expected of them.

“To the casual observer, John seems really popular, because all the kids at school know his name and are friendly. When he shows up for a school basketball game, lots of kids wave and say hello—but no one saves a seat for him, invites him along for a soda afterwards or offers to give him a ride home. All his ‘friendships’ are very superficial.”

“Gregory has difficulty entering new social situations, and we've found that a little practice helps a lot. We write a short story that outlines the new social situation, describes the appropriate emotions and includes specific verbal and physical cues. For example: It is friendly to say ‘hello’ to your friends when you see them in the school hallways. Gregory was walking to his math class. He saw his friend Sam. He said, ‘Hi, Sam!’ and gave him a friendly smile. Sam smiled back, and said, ‘Hey, Gregory.’ It's nice to say hi to your friends when you see them.”

Moving Forward, Making a Difference: Additional Resources and Strategies

A child's success in life depends upon support from many people—parents, teachers, peers and community members. Children with hydrocephalus already have a medical team in place, a group of professionals who work together to ensure optimal health. Equally important is an educational team, made up of teachers, parents, resource specialists, occupational therapists and even peers, to ensure optimal learning conditions.

Any intervention plan should cover all aspects of a child's school life: every class, recess, break, field trip, assembly and extracurricular activity. "Special education" need not be a physical place to which a student is assigned. Rather, it's a full spectrum of compensations, accommodations, modifications and strategies.

Parents

Developing positive relationships with parents is a key part of integrating a student with hydrocephalus into your classroom. Most parents have had to become experts as they've dealt with their child's medical, educational, social and emotional needs. Recognizing and validating their knowledge about their child's intellectual and social abilities helps create open lines of communication, through which a child's strengths and weaknesses can be honestly discussed.

Resource Room Teacher/Resource Specialist

By federal mandate, children with disabilities must be provided with a "continuum of alternative placements." Children who are mainstreamed in regular classrooms must be provided with supplementary services, which often takes the form of a "resource room."

The resource room is a classroom staffed by a specially trained teacher. Depending on the student's needs, the resource teacher may provide instruction in reading, language arts and math, as well as study skills. For some students, the resource room may function a bit like a study hall or home-room, where they can get assistance if they need it.

Resource programs differ from state to state and in individual school districts. In some cases, the student will meet with

“For the first two years of high school, Lisa had a ‘resource period’ every day, in place of an elective. This class was like a study hall, conducted by the resource specialist, during which she could get help with homework or gather strategies for making classwork easier. Now that she’s going to be a junior, though, she’d rather take an arts class instead—so Lisa will only meet with her resource specialist once a week.”

“At first, I was a little intimidated by leading my own IEP, but I realized what a great thing it was. It allowed me to show the people there that I knew about my needs, and that they should listen to me, rather than assume they knew my thoughts and needs. It was a big step in independence for me, taking control of my goals and education.” (Sam, age 17)

their resource teacher on a regular basis—daily, biweekly, weekly, etc. The student’s IEP will indicate how these resource periods will be integrated with his or her schedule.

Resource teachers (also known as a resource specialist) are crucial members of the education team. In addition to teaching learning strategies and providing one-on-one assistance, they also help write the student’s IEP and implement the strategies for achieving IEP goals.

Students

Very often the best advocates are the students themselves. They are the experts and their input should always be encouraged. They can best describe their needs, and can also suggest some excellent strategies. And by listening to them, we not only validate their opinions but encourage their self-expression.

Other Resources

The Hydrocephalus Association has a wealth of information on hydrocephalus, learning disabilities, the IEP process, special education and more. See Appendix D for a list of additional resources that can be ordered from the Association.

Conclusion

We envision this booklet as a collaborative process, incorporating wisdom and insight from all the parties involved: teachers, parents and students. We value your opinion and invite your feedback for future editions of *A Teacher’s Guide to Hydrocephalus*.

Appendix A

About IEPs

The Individuals with Disabilities Education Act (IDEA) Amendments of 1997, P.L. 105-17, is the federal law that ensures a free, appropriate public education for eligible children and youth with disabilities. This law is the latest of several amendments to P.L. 94-142, the Education of the Handicapped Act, and is used by school systems around the country to guide the way in which special education and related services are determined for and provided to eligible children and youth with disabilities.

Eligibility is determined by a thorough evaluation, which includes testing, an assessment of the child's medical history, the observations of professionals who have worked with the child, and consultation with parents, teachers and others.

After a child has been found to be eligible for services, an IEP meeting must be held within 30 days. An Individualized Education Program (IEP) is a written statement of the educational program designed to meet a child's needs. Every child who receives special education services must have an IEP.

The IEP has two general purposes: to set reasonable learning goals for the child, and to state the services that the school district will provide for the child.

Many people come together to develop a child's IEP. The IEP team includes most of the same individuals who were involved in the child's evaluation. Team members will include: the teacher; the parents; at least one of the child's special education teachers or resource teachers; a representative of the public agency (school system) who is qualified to provide or supervise the provision of special education, knows about the general curriculum and knows about the resources the school system has available; an individual who can interpret the evaluation results and talk about what instruction may be necessary for the child; the child; representatives from any other agencies that may be responsible for paying for or providing transition services (if the child is 16 years or, if appropriate, younger); and other individuals (invited by parents or the school) who have knowledge or special expertise about the child.

Together, these people will work to develop and implement the child's IEP.

Appendix B

Consensus Statement on Physical Activities for Children with Hydrocephalus

All children have a need and the right to be their own person as they mature and explore their world. A child with hydrocephalus is no different. It is essential that he or she be treated like any other child and afforded every opportunity to live as normal a life as possible. The shunt is a very durable device and should pose no special problems in the course of normal physical activity or childhood bumps or falls.

In general, the activities of children and adults with hydrocephalus should not be restricted. They should be encouraged to participate in regular activities, including school and after-school physical education programs and recreational sporting activities. While some neurosurgeons are reluctant to have their patients participate in contact sports, it should be emphasized that the specifics of each patient's situation are unique.

Consultation with a neurosurgeon is strongly recommended. Together, the neurosurgeon, the patient and the family should be the ultimate decision-makers regarding specific activities for each individual with treated hydrocephalus.

*—Medical Advisory Board and Board of Directors,
The Hydrocephalus Association*

Signs and Symptoms of a Shunt Malfunction

Once a teacher gets to know his or her students, he or she is more able to recognize the subtle changes that may occur if a shunt is beginning to malfunction.

The standard signs and symptoms of a shunt malfunction include the following:

- Vomiting
- Headache
- Vision problems
- Irritability and/or tiredness
- Personality change
- Loss of coordination or balance
- Swelling along the shunt tract
- Difficulty in waking up or staying awake
- Decline in academic performance
- Fever
- Redness along the shunt tract

If the teacher notices grades dropping over a period of time *for no apparent reason*, that may be an early sign of a malfunction. Subtle, unexplained changes that accumulate can begin three to six months prior to a malfunction. Some of these changes can include:

- Changes in a child's concentration level
- The child begins to have trouble understanding concepts
- The child cannot follow more than one direction at a time
- The child struggles to pay attention
- The child may be having headaches that make him or her extremely irritable, and which may be interfering with the child's schoolwork
- The child may have trouble focusing, particularly on the blackboard, taking tests or on reading assignments

It is important to note that these signs and symptoms are a change in the normal behavior of the student. A perceptive teacher can be an invaluable resource to the child and his or her family.

Appendix D

Additional Resources

Many of the following resource materials can be ordered directly from the Hydrocephalus Association. Please contact us for ordering information.

General

About Hydrocephalus—A Book for Families, a 32-page booklet published by the Hydrocephalus Association

“Creating a Circle of Friends,” by Sue Lehr, Ph.D., Hydrocephalus Association Newsletter, fall 2000

Education information packet of articles and fact sheets, compiled by the Hydrocephalus Association

“Headaches and Hydrocephalus,” Fact Sheet, Hydrocephalus Association

“Hydrocephalus,” by J. M. Fletcher, et al., in K. O. Yeates, et al., *Pediatric Neuropsychology: Research, Theory, and Practice* (New York: Guilford Press, 1999)

“Precocious Puberty,” Fact Sheet, The Magic Foundation for Children’s Growth (www.magicfoundation.org; 800-3MAGIC3)

“Social Skills Development in Children with Hydrocephalus,” Fact Sheet, Hydrocephalus Association

“The Resource Guide” (Hydrocephalus Association): A listing of 500 articles about hydrocephalus and related conditions

Teaching and Working with Children Who Have Emotional and Behavioral Challenges, by Beth DeHaven Bader, M.S., et al. (Center for Effective Collaboration and Practice; to order, call 303-651-2829)

Learning Disabilities

“Learning Problems and the Central Nervous System in Children with Spina Bifida,” by Jack M. Fletcher, M.D.

Learning Disabilities Online: www.ldonline.org

NLD on the Web: www.nldontheweb.com

“Nonverbal Learning Disorder Syndrome,” Fact Sheet, Hydrocephalus Association

IEPs

The Complete IEP Guide, by Lawrence Siegel (Nolo Press; to order, call 1-800-992-6656)

“Questions and Answers About IDEA,” www.nichcy.org

“Student’s Guide to the IEP,” www.nichcy.org

“Transition Services in the IEP,” www.nichcy.org

About the Hydrocephalus Association

The Hydrocephalus Association is a national, 501(c)(3) nonprofit organization founded in 1983 to provide support, education and advocacy to individuals, families and professionals. Our goal is to provide comprehensive services that empower individuals and families to seek out the best medical care, programs and resources that will meet their needs now and in the future.

As the nation's most widely respected hydrocephalus support group, the Association has been instrumental in creating a community of individuals, families and health-care professionals addressing the complexities of hydrocephalus in all age groups—infants, children, young adults and adults. We continually update and expand our resources to keep pace with new technologies in the diagnosis and treatment of hydrocephalus and stay current with the needs of the individuals we serve.

Hydrocephalus is a chronic condition. However, with early detection, effective treatment and appropriate interventional services, the future for individuals with hydrocephalus is promising. We invite your inquiries.

Resources

About Hydrocephalus—A Book for Families (English or Spanish)

Prenatal Hydrocephalus—A Book for Parents

About Normal Pressure Hydrocephalus—A Book for Adults and Their Families

Hydrocephalus Diagnosed in Young and Middle-Aged Adults: A Book for Adults and Their Families

A Teacher's Guide to Hydrocephalus

Directory of Pediatric Neurosurgeons

Directory of Neurosurgeons for Adult-Onset Hydrocephalus

LINK Directory

Quarterly Newsletter

The Resource Guide

Fact and Information Sheets on wide range of topics related to hydrocephalus

Annual Neurosurgical Resident's Prize

Biennial National Conference for Families and Professionals

Notes