Learning Among Children with Spina Bifida
Donald J. Lollar, Ed. D.

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INTRODUCTION

The incidence of Spina bifida in most areas appears to be decreasing in recent years. Emphasis on medical advances has been maintained with the advent of magnetic resonance imaging (MRI), bladder augmentation, new orthotics, shunt materials, etc. Still the children, adolescents, and young adults with spina bifida are often struggling to find their way toward substantive education, gainful employment, and autonomy in daily living.

Initially, this issue for Spina bifida children and parents was survival; followed by orthopedic problems, and bowel and bladder incontinence. As these young people as a group continued to experience dependence problems, professionals and parents placed emphasis on the emotional dependence which was often evidenced within the families. Paralleling these developments has been a continued effort to understand the neurological sequelae of Spina bifida, including hydrocephalus and Chiari malformation.

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Along with these difficulties, on the positive side, these young people are often socially adept and good with words. As preschoolers, they are often hard workers with courage and motivation. They do/did not begin with as many difficulties early, but these may come as more independence is expected. These early strengths set the stage for expectations of normalized functioning in daily living skills. Even assuming family dependence, it has become apparent that other factors interfere with progress toward independence.

Parents and observant teachers, health care professionals and friends have seen problems with motor skills, attention, memory and organization. Knowledgeable professionals also have known that some of these characteristics are often associated with hydrocephalus, present in most of the children with spina bifida (approx. 80-90%). Recently, however, there has begun a concerted effort to identify, understand, and begin to intervene in the learning problems often present in children, adolescents, and young adults with spina bifida and hydrocephalus.

OVERVIEW OF RESEARCH

Most research has related medical aspects of Spina bifida and hydrocephalus to scores on tests of intelligence and academics. Researchers on different continents have found common trends regarding physical aspects of Spina bifida.

1. According to the severity of hydrocephalus, intelligence and academic scores are lower. (2, 7)
2. The higher the level of the fault in the spinal cord, the greater possibility of lower intelligence and academic scores. (6)
3. Several studies indicate central nervous system infection diminishes intelligence. (5, 6)
4. Children with Spina bifida (with or without) hydrocephalus usually have perceptual-motor problems. This means that skills needing eye-hand coordination are usually below average, and may affect handwriting and doing self-care activities, such as, catheterization. (2, 6, 7, 9)
5. Since perceptual motor skills are a problem, intelligence tests often show higher scores on verbal abilities than non-verbal or performance abilities. (2, 4, 12)
6. Verbal intelligence scores are better predictors of achievement scores than non-verbal of full scale intelligence scores on a measure like the Wechsler. (4, 12)
7. Academically, reading and spelling are usually better, while math skills are often much lower. (4, 12)
8. In addition to psychological information, it has become clear that neuropsychological functioning is also affected. Neuropsychological evaluation includes assessment of areas, such as perceptual-motor function, attention, impulsivity, hyperactivity, memory, sequencing, organization, and reasoning. Several studies have shown problems in these areas. These areas may be a problem even when a child or adolescent’s overall intelligence is above average(1, 2, 4, 10)

While these results give helpful general information, most of them conclude that each child needs to be evaluated both psychologically and neuropsychologically so that their individual strengths and deficits can be identified. This knowledge can then be used to develop appropriate help for learning selfcare and ADL skills as well as educational placement academic abilities.

RECOGNIZING LEARNING PROBLEMS AND ASSESSING THEM

As we acknowledge that children with spina bifida do have learning problems, we are better able to recognize them and help. Often parents or teachers notice that something is interfering with a youngster’s success at school but they are not sure what is wrong. At this point, parents and teachers need to work closely together to figure out the various learning strengths and problems the child may have. In addition, it often helps to have a psychological evaluation, which would evaluate a child’s intelligence, academic levels (e.g. reading, spelling, math), and basic learning abilities (e.g. visual perception, receptive and expressive language skills). Because of more basic learning problems, it is helpful to evaluate neuropsychological functions. These include attention, perceptual-motor processes, reasoning and problem solving, organization and sequencing skills, and memory.

When this information is integrated, a learning profile can be developed for each youngster. This includes the child’s learning strengths and problem areas. With this information, parents, teachers and health professionals can assist the child to learn more effectively.

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LEARNING PROFILES AND IEP'S

The learning profile is important for health professionals in helping parents and children learn selfcare skills such as independence with bowel and bladder care. It is important at school for teachers to present academic material effectively and use appropriate materials. The profile also helps the school set up the Individual Educational Program or IEP when it is needed. This is one part of the Public Law 94-142 which insures appropriate education for all children who have handicaps to their learning.

Sometimes there are misunderstandings or differences of opinion among parents, school and health professionals. Since the best interest of the child is always the heart of decisions, it is important for all parties to be as helpful and understanding as possible. Parents have help if they feel their youngster is not receiving appropriate services in the schools. There is what is called "due process" which gives parents a way of appealing decisions they believe are not helpful to their child.

Several issues may come up. Often, children with spina bifida are automatically placed in regular classes, or a class for orthopedically handicapped children. While this is frequently the best placement, there are many children whose orthopedic problems are secondary to their learning problems. The "learning disability" associated with spina bifida, then, can be a major disability. The disability should be understood and addressed in any I.E.P.

LEARNING STRENGTHS

Children with physical disabilities often are described by their disability, and not by their strengths or abilities. All children have characteristics or skills better than other abilities. Any instruction should highlight relative strengths in a child's learning and personal attributes. This will also apply to academic subjects. Children usually have certain subjects in which they are better.

Beyond learning problems, a large percentage of children with spina bifida have average intelligence and strong verbal abilities. This usually allows good social skills and the ability to get along with others. Specific learning and personal strengths should be used to counter balance learning weaknesses.

LEARNING PROBLEMS

While the child with spina bifida may not be considered as learning disabled by State or Federal guidelines, "learning disabilities" or individual learning weaknesses do exist. Let's review these:

1. Poor coordination between eyes and hands (perceptual-motor)
2. Hearing or speaking but not necessarily understanding (comprehension)
3. Poor attention (attention/distractibility)
4. Restless/Fidgety (hyperactivity)
5. Not remembering what is said or seen (memory)
6. Disorganization (organization)
7. Not keeping things in order (sequencing)
8. Poor at making decisions and solving problems (reasoning/problem solving)

The following sections will describe each learning problem, and a few suggestions for helping your child or adolescent. These are only representative examples. You and your professional support members can come up with others for your child or adolescent.

PERCEPTUAL MOTOR PROBLEMS

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Children with shunted hydrocephalins often have problems with eye-hand (visual-motor) activities. Visual perception problems mean the child may have problems "seeing" things in their head, finding their way around, and generally being less coordinated. Fine-motor skills are often rather poor among spina bifida children. Together these weaknesses typically interfere with the ability to move around, use materials or tools and perform academics such as reading, arithmetic and writing.

Suggestions

1. It is very important that children have all senses stimulated - seeing, hearing, smelling, touching, tasting and moving.
2. Youngsters with spina bifida require physical exercise and help developing awareness in space. This includes rolling, turning, somersaulting, etc. These are seen as basic skills needed by children with spina bifida.
3. Beginning in the early years, help children learn basic relational ideas (up/down, in/out, right/left, top/bottom, etc.).
4. Spend time and energy on games and activities which encourage eyes and hands working together, including threading objects on a string, building blocks, legos, throwing and catching balls according to age, etc. Even games like Nintendo can be helpful in this development, if used sparingly and not as the total program.
5. In addition, encourage children to color and paint, work with clay, cut (blunt scissors) and paste.
6. Children often can enjoy eye-hand activities which are also imaginative like "take-apart" toys, or old broken clocks, radios, etc.
7. Because of difficulty in copying from board to paper, when possible, provide a printed copy of board material or allow a responsible peer to share his/her notes.

COMPREHENSION

Children with spina bifida sometimes have a hard time understanding things even though they seem to understand. This is particularly true of some kids who speak well, but when they have to explain what they said, or respond to questions, they seem disorganized, and talk about irrelevant things. They may change the subject in the middle of what they are saying.

This problem usually goes away by the time the child is about 10 years old but comprehension problems often go beyond this age. When it goes beyond this time, working to make it better is difficult. Several strategies can be used to help children who are having trouble understanding.

Suggestion

1. Use visual maps, demonstrations and simplified verbal explaining to help the youngster "get a picture" of what is being said (or read).
2. Encourage the child to assume roles and act out characters in picture story books. In this way, the child actually experiences what is happening and can understand better.
3. Begin early to help the child explore topics at their own developmental level. Ask questions that help the child stay on the topic, and let you know the child understands what they're talking about.
4. As the child begins to read, talk with him/her about what they are reading to be sure they know what they're reading.
5. Help the child capture "the main idea" of a story, movie or conversation.
6. Encourage the child to read the questions following a chapter prior to the reading of the chapter. This can help with organization and comprehension of the material by emphasizing its most important points.

ATTENTION

It is quite common for children with spina bifida to have trouble paying attention to parents, teachers, friends, tasks, etc. This at times gets mixed up with a child being emotionally self-centered and not being attentive to other people's needs. Both may be true. Inattention, however, is particularly a problem in school. Children may miss assignments, miscopy assignments or work, generally be slow in completing work (beyond visual-motor speed problems), or miss social cues from others. Children with spina bifida generally are better able to pay attention when listening than when seeing.

Suggestions

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1. Beginning in the early years encourage your child to pay attention to their room; home, yard, and neighborhood. Take walks and emphasize attention to sights and sounds.

2. Let the child know that you (parent/teacher/professional) realize she/he may have trouble paying attention. Make an agreement that you will give them a "secret sign" just between the two of you to let them know they are not paying attention. Embarrassment and conflicts are reduced and better relationships are formed, plus attention is better.

3. Be sure you have the child's attention before telling or showing them something. This can be insured by waiting for eye contact before you begin.

4. As much as possible, give the youngster a quiet place to work with few distractions. At school, a seat on the front row or close to the teacher may reduce distractions.

5. Give short assignments or chores that can be done successfully; this increases concentration.

6. Work on tasks in several short periods of time with breaks between. Let the breaks include helpful chores. Whether at school or at home, do the tasks frequently to encourage complete learning. You may try to increase the length of work periods as time goes on.

7. A system of reinforcements for work completed on time may be needed. This might require help from a social worker, nurse, or psychologist to set up a program.

8. Finally, if inattention continues to be a problem evaluation by a psychologist and pediatrician or neurologist for an attention deficit should be completed. A therapeutic trial of medication under the supervision of a physician may be considered. Medication often can allow children to pay attention better, thereby learning more and relating better.

HYPERACTIVITY / IMPULSIVITY

Children with spina bifida often exhibit restlessness and are fidgety. It is often surprising to teachers or even parents who think since an orthopedic disability slows the child down, they can't be hyperactive. But this is not surprising when one is aware of visual-motor problems. While the physical impairment may mask the restlessness, it is often present. Often associated with inattention and hyperactivity is impulsivity Children who are impulsive act before they think. This lack of stopping and thinking often gets them into trouble because they end up doing things quickly and carelessly, which gets them into trouble with adults and friends, and can be unsafe.

Suggestions

1. Set up an exercise routine to reduce physical tension.
2. The youngster should be encouraged to stop and think about what is to be done and how it is to be done. The old adage "count to 10 before you act" may be helpful.
3. Give positive reinforcement for taking a longer time on a task already successfully completed.
4. Do not require long periods of independent work.
5. Notice situations which seem to increase restlessness of impulsivity, and discuss these with the child.
6. If the behaviors continue as time goes on, as with inattention, an evaluation by a psychologist and pediatrician or neurologist should be completed. Medication, again, may be helpful when given under the supervision of a physician.
7. Provide an opportunity for "light" physical exercise or movement between periods of study or work.

MEMORY

Children with spina bifida often have difficulty in remembering things they see or hear. Even if they understand it, they may not remember it later. So it's like they have to learn it over and over again. This can happen when people are telling them things to do or when they are copying assignments from the board. It seems hard to remember one thing, while they're trying to do another.

Suggestions

1. There are different kinds of memory - seeing (visual) memory, hearing (auditory) memory, short-term and long-term - memory to name some. Most children have some parts of memory better than the others. Help the child or adolescent identify which kind of memory they're better at.
2. Help children pair (associate) things together which need to be remembered.
3. Don't hesitate to use reminders, writing events or appointments on a central calendar at home, or carrying a personal

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calendar. Computers and calculators also can help.
4. Use watches with regular alarms for remembering Ill’s for example.
5. Often one can remember better if you will say something over and over to yourself (or even out loud), like when you're learning multiplication tables or spelling words (rehearsal). Or you can help the child or adolescent think of mental pictures which they can see each time they want to remember a certain event.
6. Teach and encourage the use of note-taking, outlining and summary skills.
7. The use of a tape recorder can be helpful in enhancing memory.

ORGANIZATION

Children with spina bifida may have trouble keeping things organized. This is clearly seen when school materials, papers, etc. need to be in order. Things tend to get lost or misplaced, creating frustration, anxiety, and anger among parents, teachers and even the child, at times.

Suggestions

1. An old saying goes "Everything has a place and a place for everything." Very early in a family's life, it is particularly important to help the youngster learn this organizational principle.
2. As much as possible, parents and teachers should model organization. Keep your own things organized as best you can.
3. Reduce verbal explanations that tend to be confusing. (Don't explain everything.)
4. Keep the number of items as few as possible that have to be used at any one time - whether at school or home - e.g. regularly take toys or materials, etc. not being used out of the child's room, school locker, or desk.
5. Encourage children to think about what they will need for an activity (e.g. social, school, or self-care) beforehand and get those things together (social might include what we take on a picnic, school might include what materials and books are to be taken, and self-care might include what is needed for doing IC's).

SEQUENCING

Children and adolescents with spina bifida often have trouble keeping ideas or doing activities in their proper order. This problem may be related to not paying attention, not remembering or not being organized. The result is the same - the child, parent and/or teacher begin to feel confused and frustrated because the steps are there - just mixed-up. It may also seem that the child or adolescent doesn't understand or comprehend the situation or question. These sequencing (ordering) problems can be seen in the school subjects of math and written language. It is also seen in not being able to tell time and count change. The young person can verbally tell a good story or report what they've seen in an orderly way until they have to write it down. They cannot organize (sequence) the ideas in their head.

Suggestions

1. Early in life, help the youngster work on getting their eyes and hands working together. This is a classic early step toward sequencing.
2. Encourage dot-to-dot and other similar activities in which order and sequence are important.
3. Work consistently on time concepts and learning to do things in specific steps, one at a time.
4. Start with 2-step instructions and try to help the child develop so that they can follow 3-4 step activities. This will be particularly important when the child needs to learn to do their own bladder and bowel programs.
5. Develop "games" where the parent or teacher tries to change the order of certain everyday activities such as a) putting food down without utensils or glasses or b) instructing the child to start work on an assignment without giving the page number. Let the child, then, provide the proper sequence of events.
6. With older children and adolescents, allow them to begin scheduling daily activities, perhaps initially by writing out a schedule each day or week.
7. Provide exercises which emphasize the concept of sequence such as sequencing pictures cut from a comic strip can provide logical ordering of events. This is a prerequisite for reading comprehension.

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