Sturge-Weber Syndrome and Pediatric Therapies

The following four articles provide general information about therapies that children with Sturge-Weber Syndrome might receive: physical therapy (PT), occupational therapy (OT), speech therapy, and vision therapy.

Each article is written by a certified therapist, but because therapy techniques and philosophies can be as varied as teaching styles, please read each article with the understanding that it is part fact and part opinion. Each child's needs will vary, and with diligent work and a lot of luck, those needs can be met with a combination of private therapies (if approved by insurance) and those provided by the school system. When working with insurance companies, who often categorize therapy needs as either "developmental" or "medical," Cis Manno's definition is worth keeping in mind. She says in the speech article, "'Developmental' issues denote that the child was born with this problem and that it is going to be a lifelong issue. 'Medical' refers to some sort of insult, tumor, trauma, or anatomic problem that can be resolved in a certain amount of time. These are problems that are typically acquired and then rehabilitated. . ."

As parents and caregivers, we must be vigilant in monitoring the needs of our children. Therefore, if you believe that a child's needs are not being met, ask questions, seek information, and "question authority."

These articles were compiled and edited by Ellen Webster whose son, Byron, receives PT, OT, speech and vision therapy.

PHYSICAL THERAPY - by Clare M. Fannon L.P.T.

1. What is physical therapy (PT)?

Physical therapy is intervention that will allow an individual to move functionally through her environment.

Physical therapy (PT) is primarily concerned with gross-motor control rather than fine-motor control. (Gross motor functions include activities that involve large muscles or groups of muscles: walking, kicking a ball, jumping, using the whole arm to catch a playground ball. Fine motor functions include activities that require small muscles, usually of the hands: tying shoelaces, writing, sewing.) And even though PT is primarily concerned with gross-motor performance, in order to achieve a specific function such as using a baseball bat to hit a ball, a therapist may also have to be concerned with fine-motor skills. The therapy -- or intervention -- may be at the level of the musculo-skeletal system itself (strengthening muscles, increasing range-of-motion or

reducing pain in joints) or may be at other levels gradually progressing isolated movements to combining more complex skills so that performing a whole activity such as stair-climbing can be achieved.

2. What is the difference between PT and occupational therapy (OT)?

Physical therapists generally work with rehabilitation, reeducation or facilitation of function in large muscles or groups of muscles. Occupational therapists generally work with activities of daily living and manipulation of objects or tools. There is a lot of crossover in pediatrics as fine motor skills require a stable postural background against which they can be performed. So, often the occupational therapist is working on developing posture and balance in various positions and increasing strength in postural muscles before working on fine motor skills. At the same time, a physical therapist may also work on self care and activities of daily living.

3. What signs might indicate a need for physical therapy?

Parents might observe:

Motor delays and/or a motor-related diagnosis
Not keeping up with peers.
Not doing the same things as siblings did at similar times
General clumsiness
Lack of physical endurance for the day's activities
Avoidance of certain physical activities (climbing on a jungle gym, bike riding)
Complaints of pains in muscles/joints
Delayed walking beyond 18 months
No hands and knees crawling
Non-use of one side of the body or one limb

A school might make a referral for PT services for:

Lack of physical endurance for school day
Delayed specific motor skills in gym (no jumping/ hopping)
Difficulties on the playground
Lack of awareness of body space in class
Excessive throwing self down on floor/ leaning against walls or surfaces
Tripping or falling over obstacles
Posture in seat in class (falling off chair)
Poor fine motor skills (because you need a strong trunk and shoulder girdle to perform these skills)

4. What does a PT evaluation look like?

Examples of what takes place during an evaluation include:

Questioning the child and parent about how each thinks the child is doing
Asking the child what he'd like to be able to do
Asking the parent what she'd like the child to be able to do
Observing the child during play
Manually testing the child's muscle strength and testing the joint range-of-motion, balance skills, and overall coordination
Assessing the child's acceptance of being physically handled and determining if there are signs of tactile defensiveness
measuring the child's acquisition of gross motor skills and/or functional skills using a stan-

dardized measurement tool
assessing the child's basic sensory-motor profile

5. Are there varying types of PT treatment?

Intervention models are typically divided into:

motor control : where individual components of motor patterns are practiced, e.g. developing strength in weak quadriceps muscles or improving postural stability in a position
motor development: where therapy is based on changes of motor behaviors associated with milestones and developmental sequence e.g child moves from sitting to standing
motor learning: where functional activities are experienced and practiced leading to permanent changes in behaviors such as picking up a toy off floor and bringing it to caregiver.

Generally in a PT session one will see all of the above. The session may start with facilitating sensory arousal and attention; this may be excitatory in a child with low muscle tone or affect and calming in a child with more disorganization. There may be interventions addressing strengthening or increasing flexibility of muscles. Therapy may move on to developing appropriate balance reactions and postural stability. The majority of the session should be working on functional and developmentally appropriate activities for the child that require movement and gross motor skills.

6. How are goals and a course-of-treatment determined? What is the frequency of therapy?

Goals of therapy are discussed between the parent and therapist, according to what is important to the child and family. The therapist determines the course of therapy based on those goals and on where he deems intervention to be necessary. For instance, if a goal of therapy is to be able to walk across the room to get a toy, the therapist may have identified poor muscle strength and dynamic balance as hampering that skill acquisition. These skills, then, will be practiced in forms of exercise or functional skills which will improve muscle strength and balance.

The frequency of physical therapy is determined by how far away the child is from her goals, taking into consideration the tolerance of the child and her schedule. Usually a younger child will receive therapy that is more frequent for shorter time durations. An older child might have less frequent therapy, but the sessions might be longer in length. If the child is in school or is receiving many other therapies that would pull him away from the class or natural environment, it may be appropriate to integrate therapy into the school environment, have a home exercise program, or provide a program of activities that the school personnel can supervise

7. What is the difference in caseloads between a private and school therapist?

A private therapist who travels from patient to patient may see 4-5 children a day depending on travel time, allowing 45-60 minutes for individual appointments. A private therapist at a clinic/hospital setting can see more patients each day. And a school therapist may have a much larger caseload with sessions lasting from 30-45 minutes in length.

8. Does a child with Sturge-Weber syndrome or who has had stroke or similar condition need physical therapy?

A child with motor delays, one sided weakness or difficulty with mobility can benefit

from physical therapy. There is more need for frequent intervention initially and in the first years after the injury. However, there may be periods of time after an injury has occurred where intensive physical therapy would be indicated to alleviate an impairment that has arisen. There should always be a goal associated with the intervention, however.

9. If schools are only required to provide therapy for "educational needs," what are considered to be PT educational needs?

The scope of related services that fall under the umbrella of PT may indeed be broad in scope and should be provided by the school district if these services can support and assist the student in gaining benefit from his educational program. There are times when the PT program should also be preparing the student for meaningful employment, participation in the community, or in leisure activities. Some specialized treatments, such as hydrotherapy (aquatherapy), sensory integration therapy, and functional electrical nerve stimulation, may require specific equipment that can only be found in medical centers or clinics, and in these cases, students may need referrals to these facilities.

10. How can all of the needs of the child be addressed, even if they are not considered to be "educational"?

A parent should ask the school therapist if any other therapies are indicated for this condition, and if the answer is "yes," ask what he considers to be appropriate outside resources. A family can also ask a private physical therapist or clinic (resources to both available through the American Physical Therapy Association, see resources) to assess the child to see if they recommend a different type of therapy or if they know of research that would be relevant to this child. School therapists may not always know what is available in the medical setting.

11. How closely will the family collaborate with the therapist?

The therapist should work closely with the family whether in school or employed privately. Information from the initial evaluation should be explained promptly and the goals themselves as well as how the goals will be attained should be discussed. There should be frequent updates on progress, on the course-of-treatment of therapy sessions, and information given about exercises that can be reinforced at home.

12. What are the family's responsibilities with therapy? Is the family welcome to sit in on therapy sessions?

The family should keep the PT informed of medical appointments and let the therapist know about other medical personnel working with the child. They must also provide a current prescription from a medical doctor for PT service. Therapists generally welcome the family to sit in on therapy sessions so that activities and exercises can be explained. Specific home exercise programs given by the therapist should be practiced with the child between therapy sessions. However, if the child is not responding well in the presence of parents, it may be necessary for the therapist to work alone with the child.

13. How closely will the PT work with other therapists and the school team?

Ideally there will be regular collaboration with other team members at school, and sometimes co-treatment will take place. However, parents should be aware that schedules often do not allow for as much collaboration as the team would like and the child might benefit

from. In this case, it can be helpful for a family to initiate the use of a "journal" in which both therapists and teachers note their activities with the child and can identify what skills they wish to have practiced in other settings (for instance, practicing certain language skills while doing gross motor work). A journal is also recommended as a forum for problem solving. If both school and private therapists are involved in a child's treatment, it is very helpful for them to collaborate because children react differently in different settings.

14. Some insurance companies decline to pay for PT services because the child's needs are deemed "developmental" rather than "medical." How are these distinguished in PT?

When services are considered developmental, it is generally because the condition is congenital, with no defined injury. This is often the case with a child with developmental delays such as Down Syndrome who will gain milestones but at a slower rate than normal, although PT will definitely speeds the process of gaining muscle strength. It is then helpful for the physician to order PT for a condition known as hypotonia (low muscle tone), equilibrium disturbances, etc. If the child has a medical diagnosis with a definite onset of the condition such as cerebral infarct or hemorrhage or a surgical intervention, PT will more likely be covered. Insurance companies also will deny PT when they see no progress being made, or when they consider therapy to be maintenance in nature; if interventions such as passive stretching and range-of-motion could be performed by a caregiver.

15. How much is too much therapy?

Ideally, the frequency should fluctuate according to the child's needs. If the child is becoming fatigued or overwhelmed by the amount of therapy and therapy is preventing the child's participation in childhood activities such as play, naps or peer interaction, therapy should be modified. Although motor-learning research indicates that skills are learned only by repetitive practice, practice does not need to be in therapy sessions. In fact, it is likely that a child will be more motivated to perform in a natural environment such as walking to catch up with his peers, in a Mommy and Me class, or simply playing with siblings.

16. How can you tell if therapy is working and when is therapy completed?

There should be a good "fit" between child and therapist and therapist and parent with open communication. Some therapy approaches may not suit an individual child or meet the needs of a family. If the therapist is not knowledgeable about a specific therapy it may be necessary to change therapists. Goals should be reevaluated about every 6 months (annually in school), and they should be written with a specified time period for completion clearly identified. If the goal is not achieved, there should be discussion about why it was not accomplished. Therapy is completed when the child is able to participate to her maximum potential.

17. What other types of therapy might a child receive?

Hippotherapy - is also called therapeutic horseback riding. It was started in England when it was found to be very helpful in developing trunk muscle strength and stability, balance reactions, and improved flexibility. The warmth and girth of the horse can induce relaxation of spastic muscles, and the rhythm of the horses' strides can facilitate more mature patterns of human movement. The ability to control the horse improves self- confidence and the bond between horse and rider promotes empathy and language. There are specially trained equestrians and assistants who work with hippotherapy, and often a

physical or occupational therapist is present to evaluate the client's needs and make suggestions for the exercise program. This is a valuable therapy adjunct to traditional therapy and creates a life-long leisure pursuit.

Aquatherapy/hydrotherapy - combines flexibility, strengthening exercises, and ambulation in the water. Swimming skills are not necessary, as the pool is usually shallow enough to allow walking. Flotation devices are used to promote relaxation or to resist water pressure, thus strengthening muscles. A physical therapist or a specially-trained swimming instructor can lead a session.

Sensory Integration Therapy - was proposed by Jean Ayres in 1979. It is the ability of the central nervous system to receive, process, and organize sensory information from the environment in order to produce a suitable adaptive behavior. Intervention and therapy is based on designing an environment with activities which are meaningful and fun for the individual and which provide a controlled sensory input in order to elicit an appropriate adaptive response.

Aspects of sensory processing that can become disordered include: over/under or delayed registration of sensory input, impaired discrimination of specific sensations, poor modulation, causing over/under arousal, shut-down, sensory defensiveness characterized by exaggerated avoidance to specific sensations or emotional outbursts, and fear/flight reactions. Sensory motor systems that are involved include: the vestibular system which has a major role in postural control and head orientation; the proprioceptive system which tells us the position of joints and length or tension in muscles and thus our body position in space; and the tactile system which provides information on skin pressure, pain and temperature. Appropriate processing leads to praxis or motor planning -- how we carry out routine motor tasks and how to execute novel motor patterns.

NDT (Neuro-developmental Treatment) - was developed by Berta and Karel Bobarth who worked with children with cerebral palsy in England. It is based on decreasing the effect of spasticity and primitive reflexes, by positioning and increase voluntary movement by guiding body through specific movement patterns, facilitating appropriate weight shift. It tends to be rather passive initially, so the child can feel the movement, but manual input is decreased with time. Therapy is organized in a developmental sequence based on acquisition of normal milestones.

18. Are there other therapies we might hear about?

There are many other therapies practiced by physical therapists. Some names one might hear include:

Feldenkrais was developed in Israel by Feldenkrais, a type of massage and movement therapy that has been used with a variety of movement disorders, especially cerebral palsy.

Myofascial Release is deep pressure over fascia which surrounds muscles and organs, thought to increase flexibility of muscles shortened by spasticity and non-use.

Cranio-sacral therapy is similar to above working on pressure points around the cranium and sacrum to effect changes in rest of trunk.
Conductive Education was developed by Peto in Hungary for children with cerebral palsy. Facilitators are often teachers who provide cognitive input in the form of specific instruc-

tions. Movements are broken up into small tasks.

Constraint-Induced Movement Therapy is used to promote movement in the involved side of a hemiplegia. The non-involved side is constrained in a splint and sling for long periods of the day, and functional activities are given to encourage use and to strengthen involved arm or leg.

19. What are the educational requirements necessary to become a PT?

The minimal requirement is a bachelor in Physical Therapy, but most programs are moving to an entry-level Master's in Physical Therapy (post BSc). There is also an MPT degree often with a specialist certification, also an entry level Doctorate and a full DPT.

Occupational Therapy by Kathy Blair, OT

1. What is occupational therapy?

Occupational therapy (OT) is the art and science of using purposeful activity to enhance one's "occupation" by minimizing the effects of disease, injury, congenital defect, disability, developmental delay and/or deprivation. A child's "occupation" includes play, learning in school, and participating in home and community activities with family or friends.

2. What are indications that a child might need OT?

Signs that might signal the need for OT include the following:

* Delay in developing motor skills (gross motor/body movement such as crawling and walking, and fine motor/ manipulation such as writing and sewing)
* Sensory defensive behaviors
* Poor self regulation (over-reactive or under responsive to certain stimuli /situations)
* Difficulty "planning" new movements
* Poor organizational skills (desk is a mess, can't keep track of belongings, etc.)
* Difficulty with feeding skills oral motor function
* Lack of independence in self care skills (dressing, toileting, hygiene)
* Difficulty with visual-perceptual skills (body in space, figure-ground discrimination, etc.)
* Need for adaptive equipment to improve or maintain function
* Written output (handwriting, keyboarding)

3. If a referral for OT services is made, what might be involved in an initial evaluation?

School personnel may make a referral for evaluation for any of the difficulties listed in #2 above. Then an Evaluation Planning meeting would take place with the parents and school personnel, after which a full evaluation would be scheduled. As part of that evaluation, parents may be asked to complete a developmental history and a sensory profile questionnaire. The OT practitioner would likely ask the parents and teachers what the child does well and what the child has difficulty doing independently. The OT may also observe the student in a variety of school settings and conduct standardized and/or informal tests. When completed, the report would indicate the child's abilities and areas of concern and would make recommendations for addressing the child's needs.

4. What about course-of-treatment, frequency, and differences between school and private therapy?

In most states a prescription from a physician is required for delivery of OT services. This is based on the Practice Act (or licensure requirements) specific to each state. OT practitioners who work as a member of a school-based team should collaborate with the parents, teachers and other members of the team to determine the priorities for goals and objectives for the child's Individualized Education Plan (IEP). The extent of collaboration varies widely from school to school and is highly dependent on factors such as the amount of time set aside for team meetings, administrative support, rapport between team members, and parent involvement.

In the school setting, OT is a related service provided to allow the child to benefit from her special education. The focus of treatment, type of service delivery (direct, consultation, monitoring), and frequency of services depends on variables such as the age of the child, type of disability, type of treatment required, and the ability of the teacher to include the child in educational activities.

A therapist in private practice may have greater latitude to address concerns not covered under the "educationally related" umbrella and may often have specialized training in areas such as Sensory Integration, Cranial-Sacral therapy, Neuro-developmental Treatment (see web addresses for more information).

5. Are there caseload differences between private therapists and school therapists?

Caseloads of OT practitioners vary greatly depending on his level of training, the complexity of students' needs, the number of OT assistants, the amount of time per week spent doing evaluations, travel time from school to school, etc. School-based OTs usually schedule children for ½ hour treatment sessions, although children who require more time to "warm-up" (children with abnormal muscle tone, for example) may receive longer treatments. Caseloads for a full-time, school, therapist can range from 20 to 40 students. A private therapist would likely have more authority to determine his schedule and caseload.

6. Is it reasonable to think that a child who has stroke-like symptoms (hemiplegia) or has had brain surgery such as a hemispherectomy will need the services of an OT?

A child who has had a hemispherectomy or has one-sided body weakness would likely require OT as an educationally related service in order to participate fully in the educational curriculum and school-related activities (physical education, music, art, recess, etc.). Treatment might address issues related to mobility, fine motor/manipulative skills, visual perception, self-care, written output, and/or sensory based concerns.

7. If schools are only required to provide therapy that pertains to the child's education, how are "educational needs" determined? Is it realistic for a parent to expect a school therapist to recognize and advise them if additional therapy would be helpful?

The bottom line is, parents should feel free to ask a physician (such as a physiatrist who specializes in rehabilitative medicine) and the OT whether the child's needs are being met and whether private therapy is recommended. Many children who are followed regularly by

a team of specialists have complex needs that cannot be fully addressed within the realm of school-based therapy.

8. Do you expect families to watch or participate in therapy? What are families' responsibilities with therapy?

Most schools welcome parents at any time who wish to observe the child's educational program. At the same time, they are also aware that many parents work fulltime and are not available to observe classroom activities or therapy sessions on a regular basis. In such cases an appointment can be set up to demonstrate specific skills the therapist wishes the family to carry over at home. Written/illustrated activity ideas can also be sent home.

Being a parent is responsibility enough for most people, however, a therapeutic role for parents emerges in the case of a child who needs things such as daily range-of-motion exercises, positioning to prevent deformity, or a specific program to decrease sensory defensiveness.

9. How closely can an OT be expected to work with the family, the teacher, and with the child's other therapists?

In the optimal situation, an OT would communicate regularly with all other members on the child's team (parents, teachers, other therapists and care providers). Unfortunately, the educational system as it is today does not recognize nor build in the time necessary for optimal collaboration. One or two ½ hour treatment sessions per week does little to "change" a child. It is the overall management of the child's program and the regular carry-over and practice of new skills on a daily basis that make a difference over the long term.

10. If an insurance company declines to pay for services because they deem the child's needs to be "developmental" versus "medical," what does this mean in terms of OT?

If the school-based team (of which parents are a part) determines that OT is an educationally- required service, it will be provided regardless of insurance. Proof of "medical necessity" – a medical diagnosis or clearly defined medical condition -- from the child's physician is often required for private therapy to be covered by insurance. The child's needs might be determined to be "developmental" if development is globally delayed (i.e. Down Syndrome) or if no specific diagnosis has been made.

11. How much is too much therapy?

The amount of therapy a child receives needs to be balanced between adequately addressing the child's therapeutic needs and allowing the child to participate in typical developmental activities with his peers. When a child becomes over-fatigued or cannot attend a friend's birthday party because of therapy, the parents might be wise to take a look at the child's schedule and let the child be a child.

12. What are your thoughts on hippo and aqua therapies?

Hippo therapy (therapeutic horseback riding) provides a wonderful opportunity for a child to receive the benefits of the horse's movements to promote balance reactions, trunk

stability, and muscle strengthening while building self esteem through caring for and relating to the animal.

Aqua therapy in a shallow pool uses the body's natural buoyancy and the neutral warmth of the water to promote relaxation, movement patterns, strengthening and self esteem.

13. What are the different types of OT treatment?

Depending on the specific training of the OT practitioner, the following types of therapeutic interventions may be used in addition to developmental and sensory-motor based treatments (please see the PT section of this information for more information about these therapeutic approaches the web resources for contact information):

Cranial-Sacral Therapy
Myofacial Release
Neuro-developmental Treatment
Sensory Integration
Wilbarger Protocol is used to reduce sensory defensiveness. This intervention has been incorrectly referred to as the brushing program in the past. The program incorporates a regimen of tactile input via a specific brush, followed by joint compression to reduce a child's sensory defensive behaviors.

14. What are the educational requirements of an OT in the United States?

An occupational therapist needs a minimum of 1) a bachelor's degree from an accredited OT college; 2) at least 6 months of internship/fieldwork in various practice settings; and 3) successful completion of a national certification exam. AOTA (American Occupational Therapy Association) is also looking at proposals to make entry-level OT education a master's degree. An occupational therapy assistant usually attends a 2-year program and also completes fieldwork and a national certification exam.

15. How can you tell when therapy is working or completed?

Therapy is working when the child is able to more independently and/or efficiently complete functional tasks. Therapy is completed when the child's goals have been met or when he has plateaued and needs a break from therapy. Direct therapy services will often be phased out over time based on the child's needs and progress. Consultation and monitoring with other providers may be used as a way to modify programs and monitor the child's progress before discontinuation of all therapy services.

16. How can you tell when you might need to change therapists?

Confidence in your child's therapist, including specific training in therapeutic interventions and a comfortable rapport, are important when selecting a private OT practitioner. A parent may wish to change therapists when the child appears to need a different approach that another therapist is more qualified to provide. However, changing a school therapist may be difficult because school assignments rather inflexible. Unfortunately the therapist with the most experience or specific training may not provide services at the school your child attends.

Speech Therapy - by Cecilia J. Manno, MS, CCC/SLP

1. What is speech therapy?

Speech therapy is available to any person with a communication disorder. Communication disorders are defined as an impairment in the ability to receive, send, process and comprehend concepts of verbal, nonverbal and graphic symbol system. A communication disorder may be evident in the processes of hearing, and language and/or speech. The disorder may be severe to mild and be developmental or acquired.

2. Are hearing and speech issues related?

A speech evaluation will determine if a hearing evaluation is needed and if other problems may exist such as auditory processing disorders. This may take some time with treatment to determine whether central auditory processing is a component of the speech/ language problem.

3. What are signs of speech concerns?

In general terms, the most obvious reason that a parent may inquire about speech therapy is that their child is late in developing expressive speech or that noone is able to understand their child when he talks.

A school may refer for the same reasons or if the child does not do well on a speech screening. It is mandated in the state of Pennsylvania that all children going into kindergarten have a speech screening.

Specific speech-related problems include:

articulation disorder – atypical speech sounds resulting from a child substituting, omitting, adding, or distorting sounds
fluency disorder – speaking patterns that are characterized by an atypical rate, rhythm, repetition of sounds, syllables, words and phrases
voice disorder – either excessive or reduced use of vocal qualities such as pitch, loudness, resonance, and/or duration

Language disorders can be divided into three types:

1. **Forms**
   phonology – the sound system and rules regarding sound combinations
   morphology – the structure of words and the construction of word forms
   syntax – the order and combinations of words that form sentences

2. **Content**
   semantics – the meaning of words and sentences

3. **Function**
   pragmatics – a blending of the above that combines to make language functional and socially appropriate

4. If a referral is made, what is involved in an initial evaluation?

An initial screening would combine a standardized test of articulation, a language

screening, an oral mechanism screen, an assessment of fluency, resonance, voice characteristics, and possible a hearing screening, depending on where the evaluation is performed.

5. How are goals, course-of-treatment, and frequency-of-treatment determined?

The goals and treatment are determined by the areas of deficit on objective measures as well as areas of difficulty demonstrated on a daily basis.

Frequency of sessions is determined by the severity of the deficit, the time of trauma or insult and how it effects recovery and the child's learning "style." The school system has guidelines on treatment that may be determined by the state. Most private therapists determine frequency of sessions according to the guidelines of ASHA (The American Speech-Language-Hearing Association) and according to the cooperation of the insurance companies.

6. What are the caseload differences between a private therapist and a school therapist?

Typically the state determines the maximum number of children that a therapist can see in the schools. Private therapists usually set their own caseload sizes, and many private therapists may be able to provide increased number of treatment per week, if needed, since the therapist is defining her own caseload size.

According to ASHA, in 1992 a full-time, school-based, speech-language therapist in the United States saw an average of 52 students. The caseload ages were typically: 68% ages 6-17 years old; 26% 3-5 years old; and 3% birth-2 years old.

7. Would a child with one-sided body weakness caused by a neurological disorder such as SWS or one who has had surgery such as a hemispherectomy be considered a good candidate for speech therapy?

Yes, and as the child gets older the linguistic demands in receiving messages, sending them, processing and comprehending in spoken, written and nonverbal communication necessitates continued evaluation of these processes.

8. What are the primary reasons a child might have speech issues – are they typically neurologically, motor, and/or cognitively based?

Neurologic and cognitive issues are often used interchangeably since neuro deals with problems in the brain and spinal cord and cognitive issues re typically learning based.

Motor speech disorders can stem from a variety of issues:

dysarthria: a group of motor speech disorders that result from deficits in muscular control of the speech mechanism due to peripheral or central nervous system damage. The type of dysarthria can be localized to a variety of tracts (lower motor neuron, upper motor neuron, cerebellu, extrapyramidal, etc.)

apraxia: disruption in the planning and programming of voluntary, complex motor activ-

ity for speech production

stuttering: disruption in the forward flow of speech production, from sound-to-sound or syllable-to-syllable within a word

The primary reasons that a child can have a speech disorder can be traced to a problem in the respiratory, laryngeal or supralaryngeal areas which are the primary subsystems of speech production. Speech issues can be purely anatomic such as a cleft palate, motor (above), neuro or cognitive which will be demonstrated with receptive and expressive language problems, phonatory (articulation problems), and speech disorders which may be due to vocal nodules.

9. If schools are only required to provide therapy for 'educational needs," what and who determines these needs, and if therapy outside of the school setting is needed, can a parent count on the school therapist to identify these additional needs and point them in the right direction?

Treatment should help the child improve deficit areas and communicate in any environment. The notion of "educational needs" is the terminology in which goals are written. For example, if a goal regarding feeding is written, and if the way in which the child's GI system is effecting her oral-motor movement is mentioned, that is considered "medical" even though it may be the primary reason for the oral-motor involvement.

The school therapists can make these observations/recommendations, but it's dependent upon the individual therapist as to whether or not he will.

10. How closely could a speech therapist be expected to work with the family, the school, and with other therapists?

The dynamics of how closely any therapist or teacher works with the family is dependent upon how much time each wants to give. Some people punch out at 5:00 pm.

11. Sometimes insurance companies decline to pay for speech services because they deem the child's needs to be "developmental" versus "medical. " What is the difference?

"Developmental" issues denote that the child was born with this problem and that it is going to be a lifelong issue.

"Medical" refers to some sort of insult, tumor, trauma, or anatomic problem that can be resolved in a certain amount of time. These are problems that are typically acquired and then rehabilitated in a certain amount of time.

12. What is augmentative communication?

Augmentative communication systems, such as braille and sign language, refer to another means of communication used to compensate or facilitate for the impairment and disability patterns of individuals with expressive or language comprehension disorders.

13. What does sensory motor refer to?

Sensory motor treatment influences both the afferent nerve fibers -- or sensory neurons

– that carry impulses to the central nervous system, as well as the efferent – or motor nerves – that carry impulses away from the central nervous system. A sensory motor approach is a theory of treatment. It is used quite a bit in neuro-developmental therapy (NDT) (see resources) to influence muscle movement patterns.

14. Do parents observe your sessions with children? What are the family's responsibilities with therapy?

Sitting in on therapy sessions is very helpful when teaching the family techniques thta improve function or how to increase certain language or speech concepts. Certainly improvements are most functional when carried out in everyday life. This can only be practiced outside of the treatment session.

15. What are the educational requirements for speech therapists?

A speech therapist goes through four years of college to earn a bachelor's degree. In some state you can teach in the schools with a BA/BS. A Masters (MA/MS) is obtained with 1-2 years of graduate school and practicum/field work in adult and child language disorders. Then to earn the Certificate of Clinical Competence (CCC), you must do 9 months to 1 year of work under the direction of a speech therapist who has his "C's," and then take a national exam. You are only permitted to work in the hospital or private-practice settings if you have your C's or are in your clinical fellowship year.

16. What questions might a parent ask a speech therapist prior to beginning a child's treatment?

Ask if she has treated children with your child's disorder. Ask what experience he has and in what settings he has worked. Ask what her expectations are in terms of carryover work and how information about the child will be exchanged.

17. How can you tell when therapy is working? Completed?

Hopefully you will see steady progress with functional use of skills. Evaluating the progress is often hard to determine, especially when the therapist is trying to identify the best learning modes for the child. If a child is functioning communicatively 80% of the time in his environment, treatment may be completed.

18. Are there ways to know when you might need to change therapists?

Yes. If there are limits to the therapists's skill in an area that a child needs, it might be time to change. And certainly is there is a poor working relationship between the therapist/child/parent it's time for a new therapist.

Vision Therapy - by Sharon Maida, Ed.D.

What types of vision therapy might a child receive?

A child may receive therapy from a teacher of the visually impaired (TVI) -- someone who adapts the educational needs of the child to take into consideration the visual functioning of the child; and/or from an orientation and mobility specialist (O & M) -- a person who, considering the visual function of the child, helps her learn about space and movement around environments both familiar and new to her. O&M is also known as "peripatology." Vision services include:

Vision Therapy: When an assessment of visual function indicates that an instructional program would help a child with low vision, and these approaches might be employed by a TVI:

vision stimulation (for example, having a child follow a flashlight using varying, colored filters)

visual efficiency (determined by using tracking and scanning assessments, changing the width of lines, and introducing activities that require the child to view objects from a variety of distances)

vision-utilization instruction (the therapist works with the child's vision, identifying the point where it can't be used in isolation without the child relying on secondary senses such as auditory and tactile cues)

O & M: A child's motor function and residual vision impact the child's ability to move comfortably around her environment. Initially the therapist would determine how, compared to the norm, a child uses gross motor skills and how, in turn, vision effects her mobility. The O&M teacher would stimulate the child's spatial, psychomotor and motor-skill development by first helping the child decode what is in their space and then using that information to learn to move through that space. First the space is observed, then the movement is planned, and ultimately the move is made. For example, an O&M teacher might help a child independently travel to a certain classroom by using what is within their sight, "look for the red exit sign and go two doors further on the right."

Residential program: In some cases, usually better-suited for the multiply-handicapped child, day programs may be the best place to receive vision therapy where both O&M instruction and TVIs are available. Other services such as occupational therapy (OT), physical therapy (PT) and speech therapy can also be provided there. Examples of such schools are the Perkins School for the Blind outside Boston, the Overbrook School for the Blind, near Philadelphia, and St. Joseph's in Jersey City, NJ.

2. Is it reasonable to think that a child who has glaucoma, has stroke-like symptoms (hemiplegia) or has had brain surgery such as a hemispherectomy vision therapy services?

There are all degrees of visual loss/dysfunction, but certainly a vision assessment should be done if one of these conditions exists. Functional vision assessments (FVAs), such as the Oregon Project and the Carolina Curriculum, are extremely useful because they look at tasks that are done on a day-to-day basis, and the results are then compared to a somewhat normative population. These tests differ greatly from acuity tests which are generally performed from a chair in a controlled environment, because as you add more function -- movement, balance, motor planning, fatigue, and vision use -- it becomes more difficult for a child to compensate for vision deficits, sod the true nature of their loss can be observed.

3. What are the signs that vision therapy might be needed?

Certainly if a child is severaly visually impaired, a vision assessment should be done. But often more subtle clues exist:

Bumping into objects -- either from one or both sides of the body

Reaching for something and either over- or undershooting it (called prehension, is often present with depth perception issues

Tripping over objects at ground level

Degenerative vision problems may be indicated if children who are verbal ask questions about objects that are right in front of them

4. If a referral is made, what is involved in the evaluation?

The child's level of functioning is observed at home and in other environments they frequent such as school. Some of the things observed are:

movement itself
how motor skills are used
movement between rooms
strategies to attack and perform fine-motor skills that are age-appropriate
self-help skills (for instance, we look to see if a young child uses the pincer to pick up cheerios and accuracy which tells us what they are seeing functionally)
if a baby is being changed, does she reach for something of color within a normal range of vision

5. If an insurance company declines to pay for services because they deem the child's needs to be "developmental" versus "medical," what does this mean in terms of vision therapy?

Vision loss is medical. For a blind child or one with low vision, therapy is critical. Children are expected to maneuver through our very visual world, even with vision loss. We know vision therapy works. It strenghten a child's skills by giving them tools for life.

Physical therapy (PT), occupational therapy (OT) and speech therapy services are generally provided through a school. What about vision therapy?

Vision therapists and O&M instructors are usually contracted by the school on a case-by-case basis. Schools can choose to either contract through a private therapist (if they are available in the area) or through a state-based agency such as a Commission for the Blind. Generally speaking, blindness and low vision are low-incidence handicaps, so it isn't necessary for school districts to hire full-time vision therapists.

7. Is there a difference between the caseloads in private practice and those of a government agency? Do state agencies generally provide therapy or are they considered more as consultants?

Private therapists have direct control over the number of clients they accept, so their caseload number depends on how much service each client requires. An agency-based program, however, usually requires a TVI or O&M specialist to service clients based on either: a) a specified geographical area; or b) a specified number of cases. When an agency-based TVI or O&M specialist is faced with a large caseload, the needs of all clients must be weighed and the schedule divided into cases that can be handled through consultations, those that can be aided with in-service training, and those that require direct service. The reality is that government-funded programs have limits; the specialists must be shared among all who qualify for services.

8. How are goals and the course-of-treatment determined? How is the frequency of treatment determined, and can this differ between school and private therapy?

Both the goals and the course-of-treatment are determined through a TVI and O&M's observations, an understanding of the level of functioning vision available to the child, the nature and degree of severity of the impairment, and from screening and evaluation results. The frequency of sessions depends on several factors such as the child's schedule,

the school therapy schedule (we wouldn't want to see a child who is exhausted), the level of visual function, current goals (will they be making a transitional move to preschool or other changes), as well as the therapist's existing schedule. In an ideal world, the frequency would be the same regardless of whether the services were provided privately or through an agency.

9. If schools are only required to provide therapy for educational needs, what are visual "educational needs?"

How a child functions in class with vision and how it impedes learning is the basis of their educational needs. Educational needs include:

the child's ability to recognize normally-sized pictures, letters or print used in the curriculum

the child's ability to move independently through the school

difficulties caused by glare or other lighting conditions, cafeteria and playground concerns

Vital vision issues not considered educational include:

participation in week-end sports activities

general mobility challenges outside of school settings such as movement into a doctor's office or the public library

reading, watching television, working on a home computer, and summer-camp programs and schedules

10. How can a parent identify and address a child's needs that fall outside those defined as "educational"?

Parents, as advocates, can come to the school and see what is being done there. AER (Association for Education and Rehabilitation of the Blind and Visually Impaired, see web addresses) can supply you with a list of providers in your area who are certified TVI and O&M instructors who may also do home visits. And word-of-mouth is always a good way to get information.

11. Can school therapists be expected to make recommendations for additional services?

Because vision needs aren't restricted to school environments, a therapist should help the parent know if the needs were not being met through the school and also let the school district know if the IEP (Individual Education Plan) is inadequate. If, however, a parent does not feel confident that this is happening, the parent should ask the question directly and frequently.

12. Should families watch or participate in therapy sessions and practice what has been worked on? What are families' responsibilities regarding therapy?

Parents can be a part of the session when possible, although sometimes there is a need to work with a child alone. Families are an important aspect to the work of O&M because the skills a child needs to learn affect every aspect of the child's life. This is also true for self-help skills and the role of the TVI.

How closely could a vision therapist be expected to work with the family? With a school teacher and therapists?

A vision therapist is very much a part of the educational team and should work closely with all of the above. It is our job to help everyone who works with the child to understand the strengths and the needs of the child.

14. Are there times when a therapist should be changed?

A red flag should go up if a child does not respond to the therapy, if there is a personality conflict which cannot be resolved, or if the therapist cannot or will not integrate with the team.

15. What are the educational requirements of vision therapists?

Almost without exception, an O&M instructor is required to have a masters degree in Orientation and Mobility and should have an O&M certification by AER, which is renewed every five years.

TVI and O&M instructors are professionals who have the same competencies as a teacher of sighted children plus a sequence of specialized programs to address vision needs including: medical knowledge involving anatomy of the eye and implications for education and development; counseling regarding vision and adaptation of skills; knowledge of instructional strategies; skills in teaching O&M; the ability to teach listening skills and computer introduction; curriculum adaptation and development; assessment and evaluation; and the ability to work as integral part of the child's "team."

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