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SAMPLE



Family-Professional Partnership

The relationship between family members and professionals is the heart of any program. Each person brings to the relationship unique skills, gifts, and knowledge. Utilizing all of these collective talents will result in positive outcomes for the benefit of the family. A partnership implies equal power and equal responsibilities and yet this may take some time to establish. Mutual respect of what each person has to bring to the relationship is vitally important.

Attitude of collaborative partnership

Each family is unique, with a history of culture and beliefs that make them distinct. Sometimes these differences can create tension and difficulties in the relationship. As professionals acknowledge this they should strive to listen to and understand the parent's position. True collaboration is based on respect and trust, which will enable the partnership to grow to the benefit of the child and family.

Trust and respect. This occurs when professionals believe that the family is the most important element in the child's life and they are managing their situation to the best of their ability. Learning more about family values and cultural beliefs is central to "speaking the same language."

FN-21

Nonjudgmental attitude. Hanson and Lynch (2004) encourage professionals to be sensitive to and supportive of the needs of families from diverse cultural, linguistic, and socioeconomic backgrounds. Different life styles need to be accepted and not considered as an issue when working with a child and the family. Think positively about families, regardless of their personal characteristics or situation, or beliefs. In some cases a parent's philosophical beliefs may differ greatly from the standard of care.

Empathy. This emotion enables one to process what another individual is feeling and to acknowledge another's challenges.

Balancing the power. Sharing information to enable the parent to make the appropriate decision for their family will lead to empowerment. This may require some coaching and there may be cultural styles that interfere with this concept (Hanson & Lynch, 2004). Another tenet to remember is to support the family's self-confidence.

Meet the family "where they are." Provide information and support as the family is ready and interested. The information needs to be in their language and easy to understand. Attitudes of warmth and caring, confidence and a sense humor will foster a friendly relationship. Some

families who are most in need of a professional partner may be least likely to have the skills to be an active partner (Hanson & Lynch, 2004). Professionals must not neglect or give up on these families.

Communicating effectively

Effective communication is the key to a productive parent-professional partnership (Hanson and Lynch, 2004). Principles of effective communication apply to all professionals working with all families, whether or not they are parenting a child with special needs. For parents of children with special needs, the communication process may be complicated by some of the circumstances and challenges that these families face.

Communication is a two-way exchange of information, requiring a sender (speaker) and a receiver (listener). It is most effective when both the sending and receiving are active processes and when the parties involved alternate in their roles. If one party is a passive participant, or if communication becomes one-sided, the exchange of messages becomes much less effective. Active communication involves an effective exchange of ideas. Intonation, volume, facial expression, gestures, and other aspects of body language can influence how effectively a message is delivered.

Express interest. Active communicators are those who are interested in the topic and voluntarily contribute to the information exchange. Speaking is easily identified as an active process.

Listen attentively. Effective listening is also an active process. Careful attention to the total message of the speaker (words, body language, inflection) is an important foundation of effective listening. Listeners can actively encourage conversation flow on the part of the speaker.

Acknowledge speaker. Simple, sincere statements may encourage parents to share information that will enhance the effectiveness of the exchange. It may be important to rephrase comments made by parents and repeat them back in such a way that clarifies events for better understanding (e.g., "It sounds as if you wonder if he's getting enough formula each feeding."). A wealth of information can be gained by carefully attending to words, expressions, emotions, body language, and the messages contained in what is NOT being said. Acknowledge feelings. A nod or words such as "I hear you," might help parents to vent frustration.

Factors that enhance communication

In addition to active participation in the communication process, there are a number of factors that can enhance or hinder communication. Comfort and practice with the following strategies may improve communication between parents and parenting educators:

Use open-ended rather than yes/no questions. Open-ended questions or statements encourage elaboration in response (i.e., "How does your child respond when you read to him?" "What is a typical day like for you?").

Speak in the language of the family or have a translator accompany you. Remember to address the family if a translator is being used. Learn some key phrases in the family's language.

Identify the family’s concerns, priorities and hopes. Encourage the parent or caregiver to express their hopes and dreams for the child and themselves.

Allow plenty of time for parents to respond to questions. Sometimes that means being quiet. Promote a relaxed atmosphere for communication.

Avoid making assumptions. Take time to gather information through active listening.

Offer suggestions and options regarding support or services. However, it is the parent who is the decision maker for the family.

Focus on the child’s abilities and strengths. Parents need and want to hear what their child is *able to do*.

Reinforce information with printed handouts. Parents may find it easier to share information with other family members or caregivers if written handouts are available at their interest level. Try not to inundate families with paper.

Use appropriate language. The following tips exemplify a strengths perspective and focus on the “person before the disability”:

- **Always speak of the child before referencing the disability.** For example, say, a child with a disability, not a disabled child; a child with Down syndrome, not a “Down’s child,” and so on.
- **Avoid use of terms such as** “handicapped,” “crippled,” “victim,” “afflicted with,” and so on. Instead, use phrases such as “a child with a motor delay,” or “uses a wheel chair,” rather than “wheel chair bound.”
- **Avoid terms that promote pity or negativity.** A child does not “suffer from” cerebral palsy. She has cerebral palsy.

Avoid comparisons with children who are “normal.” If references are necessary, the word “typical” may seem less judgmental.

Avoid the use of acronyms or unfamiliar language. Use terminology that parents understand.

Emphasize abilities not limitations.

FN-23

Factors that affect communication when there is a child with special needs

Several factors should be considered if there is a child with special needs in the family unit. Most of these factors are related to the circumstances and challenges facing families that were discussed earlier. Other factors that may affect communication include:

Parents may be skeptical. Families may experience an extraordinary amount of input from and contact with other professionals. If a parent’s typical experiences with professionals include lots of advice or direction with very little listening, they might enter the parent-professional partnership with skepticism.

Families may be adapting. Attend to where the family is in the adaptation process. The family’s place in this process is a factor that

may affect the communication process. Each family member may differ in where they are in the adaptation process. Family members who are in the surviving stage of adaptation may have difficulty paying attention, listening, or following through.

Parents may have other concerns. Parents who have overriding concerns about their child's future may not feel that information related to a child's immediate development is currently relevant. Professionals who actively listen and read family cues effectively will adjust plans to respond to the family's immediate concerns.

Parents may be reactive. The timing of a personal visit may not be conducive to the selected personal visit plan. A parent who answers the door to someone after just completing an extended conversation with an insurance company may feel more like exploding than paying attention to developmental information. Educators who are knowledgeable about active listening and observation will be flexible and prepared to respond appropriately. Understand that parental emotional responses may be reactions to prior events.

Strategies to support families

A standard embedded in the field of families and disability is the concept of *family-centered care*. A central component of this model is to "meet families where they are" and move from that point toward the common goal of the parent-professional partnership (Hanson & Lynch, 2004).

Invite participation. Meeting families where they are is an important strategy. This is not simply a physical reference to providing services in families' homes. It is also a reference to families' beliefs, values, and understanding of their role as parents. Professionals should not remain aloof or entrenched in their own value system and perception of "where families should be." They need to meet parents "where they are," to invite their participation, so that progress can be made (Edelman, 1991).

Promote comfort. When families are in familiar surroundings during visits, they tend to feel more comfortable. Individual personal visits provide a prime foundation for a positive relationship between professionals and families. This parent-professional partnership should be based on joint esteem, respect, and equality. It is important for parents to feel comfortable in the relationship.

Respect diversity. If families' values, choices, and roles are different from those the professional practices, meeting families "where they are" may require taking a step or two outside the professional's comfort zone. And it is possible to meet and begin to communicate effectively. A helpful (and challenging!) exercise is to reflect upon and understand your own values, perceptions, attitudes and culture. Valuing diversity and respecting the choices of others creates an atmosphere of collaboration that will enhance communication.

Clarify concerns. Rephrasing a question or statement is more likely to elicit information about the event and contribute to mutual understanding. When we clarify feelings, concerns, and priorities, we develop a positive and supportive relationship.

Provide information. Information should build on existing knowledge and expand parents' views to help them feel competent and in control. Determining the family's information-processing style can be facilitated when their strengths and needs are understood.

Reframe. Redefining concerns often provides a fresh perspective and positive aspect. If a parent negatively describes a child's behavior, reframing can put the characteristic in a more positive light. For example, a child may be seen as "persistent" instead of "stubborn."

Consider appropriate parameters for your relationship with parents. Keep in mind that families with children with disabilities may be more "vulnerable" because of their child's needs and the ongoing involvement with multiple specialists or service providers. You need to recognize the family's need for privacy and integrity as they negotiate the frequency, place, time of contact, use of telephone (home, office number, or pager), and the management of contacts outside the professional context. Too much closeness from a professional may promote over-identification with the family and interfere with the professional's power of judgment. Optimal distance is the suggested position. It is a place between enmeshment and remoteness—a middle ground.

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SAMPLE



Acquired Brain Injury and Selected Neurological Disorders

The brain

The brain is a very complex organ which begins to form during the fourth week after conception and ultimately is comprised of hundreds of billions of microscopic cells, most importantly, neurons and glial cells. Neurons (gray-matter cells) are the cellular units of information processing which send electro-chemical signals along axions and enable processing through networks of connected cells. Glia are the supporting cells which make myelin (white matter constituent), which coats the axons to dramatically increase the efficiency of conducted impulses. Neurons are connected to one another by synapses at the end of the axons. The neuron has dozens to thousands of synapses and billions of synapses are involved in the processing of even simple messages.

Specific areas and networks of the brain are specialized to control specific functions. For example, one area of the brain governs movement of the arms and legs, while another area processes the information for sight, and a third deals with production of speech. The brain receives and interprets information from each of the senses, stores and processes information, and regulates all bodily activities. As a child hears language, looks at faces, touches objects or feels love, the connections between neurons involved in these processes multiply and become organized. Neuroscientists tell us that neurons that “fire together, wire together.” This means that cells and systems of cells that are activated by environmental stimuli increase their synaptic connections and become more efficient at processing, whereas those that are not activated eventually atrophy and cease to function.

SC-1

The developing brain is a vulnerable organ. Peak times of physical brain growth occur during fetal life, the first 3 years of post-natal life, and again during puberty and late adolescence. Physical brain growth and maturation underlie an individual’s developmental progression and acquisition of skills. Consequently, any serious injury to the brain can be expected to have a negative impact on a child’s development or an adult’s functional abilities.

Description

Brain damage or neurological impairment may result from any disruption in the brain’s structure or function at any stage in a child’s development. The age of the child as well as the cause, timing, and extent of the injury will influence the degree of actual brain injury. Neurological dysfunction affects

different types of developmental abilities during childhood and occurs in one of two ways:

1). abnormal formation of the brain during fetal or early post-natal life or
2). acquired brain injury later. Acquired brain injury can result from:

- trauma
- infections
- genetic-metabolic disorders
- prolonged lack of oxygen or glucose
- tumors
- strokes

Neurological impairment can occur in a number of conditions that are addressed in more detail in this manual including alcohol-related conditions, attention deficit disorder, autism, behavior disorders, cerebral palsy, cognitive delays, speech-language disorder, Down syndrome, emotional disorder, fragile X syndrome, hearing impairment, lead poisoning, motor delay, prematurity, sensory integration disorder, spina bifida, visual impairment.

This section addresses traumatic brain injury; two conditions that result in neurological problems if they are not treated properly – hydrocephalus and seizure disorder; and lastly, Tourette disorder which is another condition with important implications for childrens’ development.

Traumatic Brain Injury

Prevalence. Traumatic brain injury (TBI) is by far the most common cause of acquired brain injury in children and adolescents. Current studies indicate that the cumulative risk for brain injury from TBI for children under the age of 16 is 4 percent for boys and 2.3 percent for girls (Rivera & Mueller, 1986). Overall, TBI sufficient to result in a change in level of consciousness or functional abnormality occurs in 1 in 500 children per year (Centers for Disease Control and Prevention, 2002; Schneier et al., 2006).

Cause. TBI results from falls, sports and recreation-related injuries, motor vehicle accidents, and assaults, including child abuse (Michaud et al., 2007). The risk of physical trauma from falls and motor vehicle accidents increases with children’s ages. Non-accidental injury occurs more commonly in children who were born prematurely, as well as those born to young parents, those who live in families with various forms of dysfunction, and also in children with a preexisting developmental disability.

Characteristics

Following significant TBI, one or more of the following traits may be evident:

- Cognitive impairment, intellectual disability
- Motor dysfunction including weakness, poor balance, or gait disturbance
- Poor visual processing or visual motor coordination
- Impairments of speech-language abilities
- Frustration, impulsivity, impatience, poor judgment
- Hyperactivity, poor attention span, ADHD
- Sensory integration impairment
- Sleep disturbances

Behavioral/developmental manifestations. Brain injury may precipitate atypical behaviors along with other developmental impairments. Unacceptable behaviors may reflect gaps in cognition or may develop over time with frustration. Neurological dysfunction takes many forms including the following:

Cognitive impairment/intellectual disability. Cognitive or memory differences may reflect difficulties in one or more of the following areas: translating information, generalizing, abstraction, sequencing and organizing, initiating or following through, retaining and retrieving information, predicting outcomes, and communication.

Motor dysfunction. This includes specific muscle group weakness such as hemiparesis; balance and coordination difficulties such as ataxia; involuntary movements like dystonia and gait problems.

Poor visual processing. Inability to interpret visual information or to connect the visual in-put to appropriate motor activities such as hand-writing or manipulation of small objects may seriously impair a child's developmental functioning.

Impairments of speech and language abilities. A child may have expressive language impairments, difficulty pronouncing sounds (phonological disturbances), or be unable to comprehend language or follow a conversation. Children with cognitive differences may have difficulty communicating feelings because they may have difficulty processing what they want to say.

Impulsivity, poor attention span, frustration, inflexibility and poor judgment. The frontal lobes of the brain are important centers for impulse control, attention span, inhibition of inappropriate behaviors and other cognitive activities. Impulsivity, hyperactivity, and inability to understand cause and effect may result in poor judgment and lead to disruptive behaviors that are often mistaken as intentional. This combination of hyperactivity, impulsivity, and poor attention span is the definition of attention deficit hyperactivity disorder. (see *Attention Deficit Disorder* in this section)

Sensory processing disorder. The child may be hypersensitive and be frustrated and aggressive, or may be hyposensitive with little discomfort or pain response. Both hyper- and hyposensitivity can occur at the same time in a given child. (see *Sensory Processing Disorder* in this section)

Poor sleep/awake state regulation. Sleep problems are common. There may be difficulty going to sleep and sleeping soundly for example, frequent waking during the night, or waking too early and being unable to go back to sleep. (see *Sleep Disturbances* in the *Special Information* section)

SC-3

Information Processing Problems

Retaining or retrieving information—A child may need external cues to retrieve information. This can affect communication.

Generalizing or interpreting information—A child may have difficulty translating information from one modality into another (seeing into writing, thinking into speaking, hearing into action).

Following directions; distractible—A child may hear a specific direction, but have problems remembering the entire directive or become distracted in the process of following the direction.

Sequencing, prioritizing, and organizing—A child may have difficulty deciding what to do first. A direction, such as “Pick up your toys and put them where they belong” may be heard, but he may not know where to begin or how to follow through. He may begin something, get disrupted and not finish.

Understanding cause-effect and predicting outcomes—A child may not understand cause and effect; may not be able to compare, contrast, associate, abstract, and generalize. This often results in poor judgment. He may have difficulty with safety issues because he can't relate cause and effect (e.g., “If I light a match, I might be burned or start a fire.”). He may not realize that when he behaves inappropriately, a negative response might occur.

Prevention. Because most childhood acquired head trauma is preventable, it is essential that all children experience a healthy, safe, enriched environment. Parents, teachers, and caregivers need to be educated regarding the appropriate restraint of children in motor vehicles; safe pedestrian behavior; use of helmets for appropriate activities; prevention of falls from heights; playground injuries; pool drowning; and sports injuries.

SC-4

Strategies to support families

Each child is unique and may manifest several of the behavioral characteristics previously listed. Observe the child's behaviors with the family, help them understand the child's specific needs, and suggest appropriate strategies related to these needs, such as:

Observe the child's behaviors to determine specific needs.

What is his behavior telling us? Is his behavior due to frustration or delayed communication skills? A highly active child may need more structure, close supervision, repetition, routine, and understanding. To determine if a change in the surroundings will benefit the child, it is important to observe behaviors such as the following:

Poor state regulation. A poor sleep/awake pattern may indicate the child needs help calming himself.

- Decrease stimulation and try swaddling techniques for the infant.
- Find a quiet, dark area for sleep or calming.
- Some children sleep best with a soft soothing sound, such as a fan.

- Provide firm bedtime routine. A bath is often calming. Avoid over stimulation. Give advance warning that bedtime or a change in activity is coming.
- Reduce stimulation by removing distractions—items hung on walls, toys, bright curtains, or wallpaper.
- Seek further help from the healthcare provider or sleep specialist.

Motor delay. Brain injury may affect muscle tone and joint range of motion and result in poor motor control, poor coordination, or other motor difficulties.

- Delayed or weak motor control may indicate a need for further evaluation.
- If there are concerns about the child's gross or fine motor skills, encourage parents to discuss this with the child's physician or a motor specialist.
- Help parents to engage the child in mutual interactions involving the whole body, physical play activities, swimming, gymnastics, etc. which will promote better body awareness and the development of motor control.

Speech and language problems. The child may have difficulty expressing his needs and feelings. This may be related to information processing problems, impaired hearing, or inappropriate stimulation.

- Use visual methods such as photos or drawings to help the child express his feelings.
- Draw attention to your own emotions ("Look at my face—I'm so sad that Johnny got hurt.").
- Encourage further evaluation from a speech-language pathologist.
- Support the suggestions of specialists.
- Help parents to take time to talk to the child, to imitate his noises or words, to engage in games that involve mutual communication such as name things for the child, and any activities which promote language development in a pleasurable and naturalistic fashion.

Information processing difficulties. There may be difficulty following directions and/or understanding anything that is not concrete, such as math, money, and time. Helpful strategies may include environmental changes and positive approaches. The keys to appropriate early intervention are developing and maintaining realistic expectations and keeping an open mind about goals and strategies.

SC-5

Tips to Assist Learning

Use auditory, visual tactile (multi-sensory) cues:

- Teach appropriate responses by modeling
- Use eye contact, appropriate touch, and child's name—avoid threats
- Use animated voice (vary pitch, loudness, inflection)
- Use various cues—written lists, pictures, singing, and role playing
- Use pictures, videos, and modeling to interpret previous reactions and to discuss appropriate social responses

Provide repetition and close supervision:

- Repeat reminders and directions
- Provide simplicity—keep instructions “simple”

Give concrete, understandable directions:

- Use multi-sensory approaches to convey a message
- Be clear—for example, say, “Stand on the black line,” instead of, “Stand in line”
- Model and demonstrate what this means; use visual reminders

Use routines and consistency:

- Provide consistency and routines—this helps the child know what to expect
- Transition or unexpected changes in activities can be difficult
- Talk about what is coming next

Observe the environment and suggest helpful changes. Children who have neurological issues or seem hypersensitive to various stimuli such as touch, sound, light, or movement may react by being irritable or aggressive. When a child has “invisible problems” such as neurological impairment, it is best to try to alter the surroundings (including expectations and strategies) rather than trying harder to change the child. Offer support and choices; this brings about cooperation. The following strategies may be helpful:

- Observe the undesirable behavior
- Look for the antecedent (what occurred before) and the consequence (what occurred after the behavior)
- Observe for sensory stimulation; consider if the child is frustrated or uncomfortable; then
- decrease unnecessary stimulation
- Take notes, journal, and brainstorm ideas
- Determine what works and what doesn't work

Help the child have a positive self-esteem. Address the child's strengths and abilities. It is important to emphasize abilities, rather than disabilities and strengths rather than weaknesses. The child will benefit from encouragement and acceptance and needs to feel good about who he is.