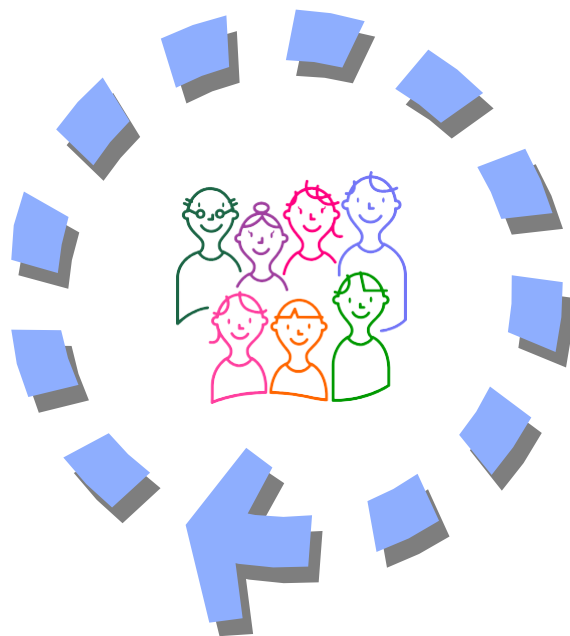




Alabama Department of
REHABILITATION SERVICES

PASSAGES



A Community-Based, Family-Centered Model for Developing a System of Care for Children and Youth with Traumatic Brain Injury



This manual is published by the Alabama Department of Rehabilitation Services, Montgomery, Alabama, and was supported in part by TBI Post-Demonstration Grant #MCJ01TB21 from the Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

This material is available in alternate format.

If I Could

If I could take this back I would

*If I could rewind the time of when
It was all good, I would.*

*Take it back to the days to when we
Said good-bye.*

*If I... If I...
If I could take it back to the day
Of when this young lady had no
Worries or cares, I would.*

*If I could take it back to the days
Of when we said good-bye to that girl
Everybody loved, I would.*

*If I could take it back to the time
Before we had our car accident, I would.*

*But only to see who I would be.
Would I be the real Nene, the old Nene?
But only If I... If I... If I could.*

J.L. Walker
Age 16

Table of Contents

Book 1: The Model of Care

Acknowledgments.....	1
Overview of Traumatic Brain Injury in Children and Youth.....	2
Introduction to the Family-Centered Service Delivery Model.....	6
Structure and Process of the Model.....	11
The Role of the Care Coordinator.....	16
PASSAGES Conceptual Model.....	24
Stage 1: Information Gathering and Assessment.....	26
Stage 2: Plan Development.....	30
Stage 3: Plan Implementation.....	34
Stage 4: Plan Revision.....	41
Stage 5: Transition and Case Closure.....	44
Appendix A: Pre-Discharge Model of Care.....	53
Appendix B: Forms.....	69
Appendix C: The Key Elements of Family-Centered Care.....	85

Book 2: Resources

Glossary.....	87
Resource Directory.....	124
Web Sites.....	139

Acknowledgments

PASSAGES is the culmination of the work of many contributors. It began in 1996 with the vision of Lamona H. Lucas, the Commissioner of the Alabama Department of Rehabilitation Services (ADRS), and Augusta Cash, Alabama's State Head Injury Coordinator. In conjunction with Charles Priest, Executive Director of the Alabama Head Injury Foundation, and Kay Herrin and Patsy Patton of Children's Rehabilitation Service (CRS), they envisioned the expansion of the state's system of care for survivors of traumatic brain injury to include a service delivery model for children and youth and oversaw the development of the grant application.

ADRS received notice of the award of the three-year demonstration grant funded through the Maternal and Child Health Bureau in 1997 and began implementing grant activities, including the development of **PASSAGES** in October 1997. Augusta Cash and J. Christine Kendall, CRS Director, served as co-directors of the project. Barbara Hankins of CRS assumed the responsibility of overseeing the development of a small statewide network of knowledgeable care coordinators and the development of a network of resources to assist children, youth, and families as they were referred for services to **PASSAGES**.

Joseph Telfair of the School of Public Health at the University of Alabama at Birmingham, Ben Arellano of Troy State University, and Kimberly Boswell of ADRS were instrumental in the development and implementation of the evaluation of the **PASSAGES** model during the grant.

Special mention should be made of Randy Hebson, Jeanette Pruitt, and Dawn Ellis of CRS, Joseph Ackerson, Arnelle Adcock, Andrea Eden, and Beth Urbanczyz, who provided technical assistance to the project in various ways.

Special appreciation is due to the current ADRS Commissioner, Steve Shivers, and the current CRS Director, Cary Boswell, for their continued support of the project and willingness to provide a permanent home for the care coordinators.

Finally, this model would not have been possible without the children and youth with traumatic brain injury and their families who were referred for services and the four project care coordinators. Their unique experiences are the heart of this project and their successes are its ultimate accomplishment.

Overview of Traumatic Brain Injury in Children and Youth



Overview of Traumatic Brain Injury in Children and Youth

Imagine waking in the morning and not remembering how to get dressed.

Imagine sitting down to eat dinner and not remembering that you just ate.

These occurrences are everyday events for many persons who have sustained a traumatic brain injury.

The Centers for Disease Control and Prevention indicates that 5.3 million Americans — a little more than 2 percent of the United States population — currently live with disabilities resulting from brain injury. More than 2 million people sustain a brain injury every year. Every 15 seconds an infant, child, teenager, or adult sustains a traumatic brain injury. Considering that each person with a brain injury has a circle of support, approximately one in every 10 individuals has had his or her life touched by brain injury.

Emergency medical services have made great strides in the medical management of individuals with traumatic brain injury. Thirty years ago, more than half of the people who sustained a brain injury died. Today that number has been reduced to 22 percent. Data from the Brain Injury Association of America suggest more people are surviving brain injury because of the following advances:

- * Better emergency response systems and faster transportation
- * Expanded use of 911 and car phones
- * Use of helicopters to transport those with serious injury to trauma centers
- * Improved medical technology and techniques
- * Safety features such as car seatbelts, child safety seats, and airbags

The Brain Injury Association of America reports that 28 percent of all children treated in trauma centers are diagnosed with a brain injury, and 2 to 5 percent will have severe lifelong functional disabilities as a result of such injuries. Traumatic brain injury (TBI) is the leading cause of death and acquired disability in children in the United States.

Due to the developmental nature of childhood and adolescence, sustaining a brain injury during that critical period presents special challenges. While children and youth with mild traumatic brain injury often do well, it is important to recognize that such an injury in the normal course of development may have significant implications. Changes from such an injury can affect their educational, vocational, and social lives. The following factors each play a critical role in the child or youth's outcome following a brain injury: age at injury, severity of the injury, cause of the injury, and the child's physiological response to the injury. Traumatic brain injury in children and youth is truly a "developing" disability, with the long-term challenges of interrupted or altered learning being revealed as subsequent developmental milestones are monitored.

Studies indicate that children who are as young as a few weeks of age are using their senses to gain insight into the world around them. Children display capabilities for memory and recognition by the time they are only a few weeks of age. During the first two months of life, memory development includes visually and auditorily recognizing things that have been previously seen or heard and expecting feedings to come in intervals. By the end of the second month, infants visually prefer faces to toys or other objects, show excitement for certain objects that move, and begin to make simple associations, such as crying leads to maternal attention and care. These are the basic developmental milestones that propel the young child toward more complex achievements of growth and development in later years. It is these complex cognitive and social behaviors which are most vulnerable following a traumatic brain injury in childhood.

For the child who sustains a traumatic brain injury, the process of recovery can be somewhat deceptive. Young children are expected to be impulsive, egocentric and unable to self-monitor their behavior. These behaviors make it

difficult to measure the impact an injury has on cognitive and social abilities. It is also difficult to measure the impact an injury has on skills a child has not yet developmentally attained. Continuity of care across developmental milestones then becomes crucial for the child injured at an early age.

Youth with traumatic brain injury often find that life becomes more complicated, especially after the onset of puberty. The transition from elementary school to junior high school becomes an academically and socially challenging time. Life becomes more difficult due to their decreased ability to process information and an inability to stay focused for extended periods of time.

Thus, although it is true that a child tends to recover physically better from the injury than an adult, it is not necessarily true for cognitive recovery. The child or youth who sustains a traumatic brain injury is much more vulnerable to cognitive, social, and emotional impairments than an adult. It is this developmental dynamic that necessitates a different approach to pediatric rehabilitation following brain injury.

As a result, support for children and youth with traumatic brain injury and their families along their developmental pathways is vital and necessary. The educational, rehabilitative, and vocational needs of children and youth with traumatic brain injury span the life cycle. For providers of services to children and youth, this lifetime consequence emphasizes the need for a systematic and coordinated continuum of developmentally anchored services and strategies to facilitate all transitions.

"People used to think of children as these wonderfully resilient beings who could adapt to even severe trauma or overwhelming circumstances. But, the truth is that they are just as adults, only sometimes it takes longer for the effects of trauma to be seen in a child."

William Singer, M.D.
Pediatric Neurologist
Harvard Medical School

Introduction to the Family-Centered Service Delivery Model



Introduction to the Family-Centered Service Delivery Model

Serving Children and Youth with Traumatic Brain Injury: A Family Affair, A Community Commitment

A person's brain is who that person is, who that person was, and who the person will become. When the brain is injured, the way the person thinks, communicates, moves, acts, and behaves changes. Children and youth with traumatic brain injury in post-acute recovery may require physical, social, psychological, behavioral, and academic support. Families of children and youth with traumatic brain injury may also have difficulties coping with the changes and needs they face. Often families and medical professionals believe that once a child or youth has left the medical environment and returned home, assistance is no longer necessary. Sometimes families recognize and voice the need for help, but are unaware of the human service systems available in their communities. Consequently, they are also unaware of the system for accessing information, referral, and/or services for themselves or their child. It is because of these prevailing needs and issues that the **PASSAGES** model was developed.

Naming the model **PASSAGES** reflects important facets of the model: multiple entry points, differing needs of children depending on the severity of the brain injury, varying needs of support as a child/youth regains function and learns new skills, and the changing family dynamics and assistance required for each new step toward recovery and reintegration into home, school, and community.

The **PASSAGES** model is designed to offer information, support, and services at whatever point a family identifies its need for assistance. Entry points include acute hospital settings, rehabilitation facilities, home, school, and community programs. This model addresses the relationship between the stages in a child/youth's life and the severity of brain injury they have sustained. It is

sensitive to the stages of adjustment and need that the family or caregiver experiences. The **PASSAGES** model provides a safe environment for child/youth and family problem solving. They have a safe harbor for addressing challenges and making decisions. Supporting both the child/youth and family is critical if the child/youth is to make a successful passage through each stage of life into adulthood.

Children's Rehabilitation Service (CRS), a division of Alabama Department of Rehabilitation Services (ADRS) and Alabama's Title V Children with Special Health Care Needs Program, in cooperation with the Alabama Head Injury Foundation (AHIF), developed a service-delivery model to address the complex needs of children/youth with traumatic brain injury and their families. Originally, this service-delivery system was to be based on the successful implementation of Alabama's 1992 Interactive Community-Based Model (ICBM) for adults with traumatic brain injury. However, due to the diversity of ages (birth to 21 years) and degree of injury served by the CRS program, **PASSAGES** developed into a care coordination model. This philosophical shift was necessary to attain the flexibility to address the diverse and dynamic needs of the target population.

Care coordination services are defined in Title V of the Social Security Act as "services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families." The core goals of care coordination as determined by a work group convened by the Association of Maternal and Child Health Programs in 1999 are improving and sustaining quality of life for the family and child, assuring access to optimal care, and improving the system of care for children with special health care needs. This group also identified key principles of care coordination as involving families as the center of the process, identifying children and families who need services, providing services that include issues beyond medical care, and developing partnerships that improve the overall system of care. One work group recommendation stressed that care coordination should be offered to families during key points of

transition in a child and family's life when the need for such coordination may be especially great. These periods would include the time of hospital discharge, entrance into day care and school settings, transition to adulthood, and when a change in health status occurs (Brown, Lake, and Varela, 2002). These goals and principles reinforce that comprehensive services for children and youth with traumatic brain injury would be most effectively delivered through a care coordination model.

Due to the unique aspects of brain injury, **PASSAGES** is divided into stages that reflect the progress that a child/youth will make between developmental milestones and toward the goal of attaining optimal or maximum potential. The use of stages to describe the process of service delivery through **PASSAGES** is based on the idea that children and youth who enter each developmental stage require continuous reassessment of where they have been, where they are and where they are going. No stage is a capsule. Each stage is related and overlapping and therefore reflects a progression of growth and development

Family-centered philosophy is at the heart of this model. Several vital features of the model capture the concern for family. First, the care coordinator provides support and assistance to the family/caregivers as well as to the child/youth. The care coordinator can intervene at various points in the service system, provide information, identify resources, and access critical service systems that support successful family community reintegration. The care coordinator works closely with the child/youth, family/caregiver, medical care providers, educators, and other local and state agencies with resources to address family needs and to enhance family strengths. Another family-centered feature is the Individualized Service Plan (ISP), which assesses and reassesses child/youth needs and development to foster optimal outcomes for the child/youth and family.

The goal of this service model is as diverse as every child, youth and family it serves. The desire is to help each person create the best quality of life given the circumstances in which they live. The wish of every contributor to this

model is to support the children/youth with traumatic brain injury and their families so that they survive the trauma of injury and thrive in the challenges they face in a new world.

"Since my child has had a head injury, my life has drastically changed. You have to educate yourself. Go with your 'mother's intuition' and make sure you are doing the best for your child. I have learned that my gut feeling is what works."

A mother of a child with traumatic brain injury

Structure and Process of the Model



Structure and Process of the Model

The purpose of this section is to describe **PASSAGES**, to provide procedural details for implementing the model, and to discuss critical issues related to the model implementation.

Referral Process

Referrals to **PASSAGES** are made by using the open public access model of Title V delivery systems. Referrals can be made by multiple entry points: parent contact/self-referral, primary care physician, specialty physician, hospital pre-discharge team, rehabilitation facility, school staff, or neuropsychologists and other therapists who may identify and obtain permission to refer for services. The pre-discharge hospital team is often the entry point into **PASSAGES** through Alabama's Pre-Discharge Model of Care for Children and Youth with Traumatic Brain Injury (see Appendix A). The care coordinator receives the referral information and initiates contact with the family. Determination of eligibility for **PASSAGES** is dependent on the needs assessment for the child/youth and medical confirmation of the diagnosis of traumatic brain injury. The Health Resource Services Administration (HRSA) defines traumatic brain injury as "an acquired injury to the brain. The term does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma, but it may include brain injuries caused by anoxia due to near drowning." Once the eligibility is established, the family is made aware of the services available through **PASSAGES**.

Use of Forms

A number of forms are used in **PASSAGES** (see Appendix B). Various forms provide structure, assess family strengths and needs, and monitor

progress. In addition, the care coordinator uses forms to develop individualized goals and service plans, promote family involvement, and determine individual strategies to meet these goals. These forms are used as guides for achieving the best possible outcomes for children and youth with traumatic brain injury and their families within a family-centered, community-based, comprehensive, coordinated, and culturally competent framework. Initially the forms are used in gathering information and documentation of baseline data. Some of the forms can be used to record items specific to the child's need and the family's need to include a monitoring and follow-up requirement. These forms are to be introduced in a manner to elicit active participation by the child/youth and family and provide them with a realistic sense of direction, participation, and goal setting. In the development of individualized goals and service plans, the child/youth and family are encouraged to participate in the development of intervention strategies and re-evaluation and revision of the individualized plans.

Family Choice

Family choice and participation are essential throughout **PASSAGES**. In the early stages of recovery from traumatic brain injury, the family will make decisions on behalf of the child/youth. It is important to remember that families are an integral part of all planning and decision making. The family's knowledge, skills, strengths, and values regarding their child's condition need to be respected and supported. When developmentally appropriate, the child/youth will be encouraged to participate in the **PASSAGES** process. This participation and encouragement will promote independence, develop decision-making skills, and encourage goal setting and future planning.

Family Participation

The family's real challenge after an injury to their child will be to access and navigate the many systems of services. Therefore, it is critical for the family

to receive support and information throughout the child's recovery process. It is the family-centered philosophy that guides the process of interaction and is essential to positive outcomes. The family's participation in the journey of recovery -- monitoring, reassessing, and strategizing with the care coordinator-- will positively influence the outcome. The **PASSAGES** care coordinators provide information, support, structure, and linkage to provider systems for the family. It is the family involvement that is a primary component for successful home, school and community reintegration. The key elements of family-centered care are located in Appendix C.

Child/Youth Participation

The child/youth's participation in **PASSAGES** ensures that his or her needs are identified and addressed. The child/youth is encouraged to have hopes and dreams for the future and independence. As the child/youth participates in his or her own journey to recovery, information is shared in a developmentally sensitive and supportive manner. **PASSAGES** promotes problem solving, decision-making and choices that support the young person along their pathway to adult life.

Length of Time

PASSAGES is not a time-driven process. A family's involvement/engagement with a care coordinator and the state's Title V agency is dependent upon one of the following event/decisions:

- * The youth becomes 21 and is no longer eligible for Title V services.
- * The youth is accepted for services through vocational rehabilitation and is no longer requesting services from **PASSAGES**.
- * The child/youth reaches optimum quality of life and no longer requests services from **PASSAGES**.

Use of Local Resources

PASSAGES focuses on development of local resources to address traumatic brain injury service needs. When possible the Title V agency will be involved to assist the family in a community-based, comprehensive, and culturally competent setting. Activities have been deliberately fashioned to promote and foster development of service systems within close proximity to children and youth with traumatic brain injury and their families. This focus is represented by the use of care coordinators located throughout the state, local service networks of health care providers, and local survivor and family support groups.

Coordination with the Medical Home

PASSAGES values coordination with the child/youth's medical home. The American Academy of Pediatrics (AAP) defines the medical home as care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent. "A child who has a medical home has a primary care physician who is working with the child's family to ensure that all medical, non-medical, psychosocial, and educational needs of the child and family are met in the local community" (American Academy of Pediatrics, 2000). This type of care is the optimal system of care for all children, including children with traumatic brain injury. Care coordinators in the **PASSAGES** model assure that children receiving services have a medical home. They interact with the medical home to facilitate appropriate and timely medical follow-up as well as services to promote reintegration into home, school, and community settings.

The Role of the Care Coordinator



The Role of the Care Coordinator

The service-delivery system providing individualized care for children and youth with traumatic brain injury was limited prior to the development of **PASSAGES**. With the implementation of **PASSAGES**, strategic systems of services can be created or enhanced to afford children and youth a better opportunity to reach their full potential.

The care coordinator arranges and coordinates services that ultimately enable the child/youth with traumatic brain injury to re-enter the community and school. The care coordinator acts as a case manager as well as an active agent in the rehabilitative process. Care coordinators assess, evaluate, and design Individualized Service Plans; coordinate services; advocate, intercede, and negotiate on behalf of children/youth and families; educate children/youth, their families, and their communities about traumatic brain injury; and facilitate as needed to create possibilities for children and youth with traumatic brain injury and their families/caregivers. This level of interaction is a primary factor in the success of care coordination and positive outcomes for the child/youth and family.

Responsibilities

Responsibilities of the care coordinator include the following:

Gather Basic Information

The care coordinator meets with the child/youth and family to assess their strengths and resources in order to determine their needs. The care coordinator gathers information about family dynamics, financial status, and demographic

information. The effect of the injury on the family is ascertained. The child/youth's pre- and post-morbid levels of functioning level in physical, educational, behavioral, social, and medical domains are also assessed.

Develop Individualized Service Plan

Based on the information the care coordinator gathers, the neuropsychological evaluation, medical records, observation and/or school evaluation, the care coordinator with the family and child/youth develops a plan of service. Family involvement is necessary throughout the development and implementation of the service plan.

Evaluate Functional Skills

The care coordinator uses available data to assess the child/youth's current level of functioning. This information may come from the initial interview, medical records, neuropsychological evaluation, and observation.

Coordinate Services

The care coordinator must work with family, the medical home, other medical professionals, transportation providers, and other community agencies and organizations to arrange services. These services may include physical, occupational, and/or speech therapies; behavior management; or medical and adaptive equipment. The care coordinator recommends community resources and acts as a liaison between the participant and service providers to individualize services.

Investigate Available Benefits

The care coordinator identifies and assists the family in accessing available benefits (i.e., Supplemental Security Income, Children's Health Insurance Program, Medicaid, Medicaid Waiver services, private insurance, community resources, and charitable organizations).

Purchase/Arrange for Individual Services

The care coordinator interacts with children/youth with traumatic brain injury, family/caregivers, service providers and professionals to address specific issues relating to home, school, and community. The care coordinator may arrange for services that promote independence and success. Considering the individual's needs, the care coordinator may arrange for services such as the following:

- * Occupational, physical and speech therapies
- * Medications, medical supplies and equipment
- * Transportation
- * Behavioral management services
- * Neuropsychological assessment
- * Educational supplies
- * Environmental modifications
- * Educational and/or training programs
- * Recreation

Provide Education and Training

The care coordinator educates the child/youth, the parents/family, extended family and caregivers, and all other service providers about the impact of traumatic brain injury on development and the anticipated impact of the injury on future development. This information may include general descriptions and statistics on traumatic brain injury, brain development and function, as well as information specific to the individual's injury.

The care coordinator educates the family and caregivers on the role of human service agencies and how families can access and advocate for services. Families may have never needed help or support from the community prior to their child/youth's injury, so they may be unaware of services or how to access them. This information may include such topics as the Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA).

The care coordinator educates parents, caregivers, the child/youth, and others on the day-to-day issues of recovery. Methods of structuring of time and activities may be suggested, as well as ideas for activities that will encourage skill building in areas affected by the injury. This level of involvement might also include addressing family adjustment issues and arranging family counseling to assist with home adjustment and trauma.

The care coordinator provides information to the community about safety and the prevention of traumatic brain injury. The other training opportunities involve professionals from the Department of Human Resources, child care centers, and recreational centers. Training and information are an important facet of working with school systems, including teachers, special education coordinators, counselors, and students.

Provide Counseling

The care coordinator assists the child/youth with traumatic brain injury and the family in problem-solving strategies. During this process, it is important for the care coordinator to recognize the culture and values of the family as they impact the family's adjustment to the injury. The care coordinator's rapport with the child/youth and family facilitates trust and participation in adjustment activities.

Set Goals

The child/youth and family are encouraged to actively participate in service delivery by helping set realistic goals that will promote the greatest degree of life quality for the child/youth and the family. Goals should be flexible enough to accommodate the ever-changing needs of the individual child and family. Initial goals will reflect immediate concerns for physical recovery. As time passes, goals may include such activities as return to school and social outlets, return to physical activity, family knowledge and acceptance of post-morbid changes in the child/youth, and return to work by one or both parents. The care coordinator

involves the child/youth and family in initiating and monitoring activities that promote independence and community integration.

Plan and Initiate Activities

As a partner with the family, the care coordinator plans activities that are appropriate for the child/youth and family and integrates them in their daily activities. Initially, the care coordinator encourages activities that are familiar and appropriate. Familiarity, structure, and consistency are vital in the early stages of recovery. As cognitive, physical, and social skills and support systems strengthen, more complex activities become feasible. These activities are monitored as part of the goal-setting status checks. It is understood that children and youth will progress along their own developmental track depending upon age, severity of injury, and causation and physiological response to the injury.

Identify or Develop Local Resources

The model may include the development of local resources to address service needs related to traumatic brain injury. The care coordinator locates and/or develops services in the community to support a lifelong system for the child/youth and family. When services or resources do not exist, the development of new resources is explored. The care coordinator may be required to provide education and training about traumatic brain injury and/or a specific child/youth's functional status to new service providers.

Attributes, Skills, and Knowledge for Care Coordination

An effective care coordinator possesses and/or demonstrates the following attributes, skills, and knowledge.

Attributes

- * Resilient and flexible
- * Organized and goal-directed

- * Self-directed work habits
- * Empathic, open-minded, and respectful
- * Assertive
- * Team player

Skills

- * Effective listening and interviewing
- * Creative problem solving
- * Mediation and advocacy
- * Assessment and analysis
- * Developing service plans, monitoring service provision, and evaluating service outcomes
- * Ability to build partnerships, network, and work with diversity
- * Effective written and oral communication/documentation

Knowledge

- * Case management/care coordination training
- * Experience in working with children/youth and their families
- * Knowledge and understanding of traumatic brain injury, including related physical, behavioral, medical, and cognitive problems
- * Interactions between a person with traumatic brain injury and his or her environment
- * Interactions between child/youth and family after injury
- * Experience with collaborating with other professionals/agencies to provide services to children/youth and families
- * Knowledge of cultural diversity
- * Working knowledge of child growth and development
- * Principles of interviewing and counseling
- * Knowledge of community resources, including those for child abuse, substance abuse and behavior modification
- * Knowledge of third party reimbursement systems/issues

- * Knowledge of agency services, policies, and procedures
- * Knowledge of public laws that affect persons with traumatic brain injury, including the Individuals with Disabilities Education Act and the Americans with Disabilities Act
- * Knowledge of the Individual Education Plan (IEP) process and state/local educational systems
- * Knowledge of assessment tools specific to traumatic brain injury

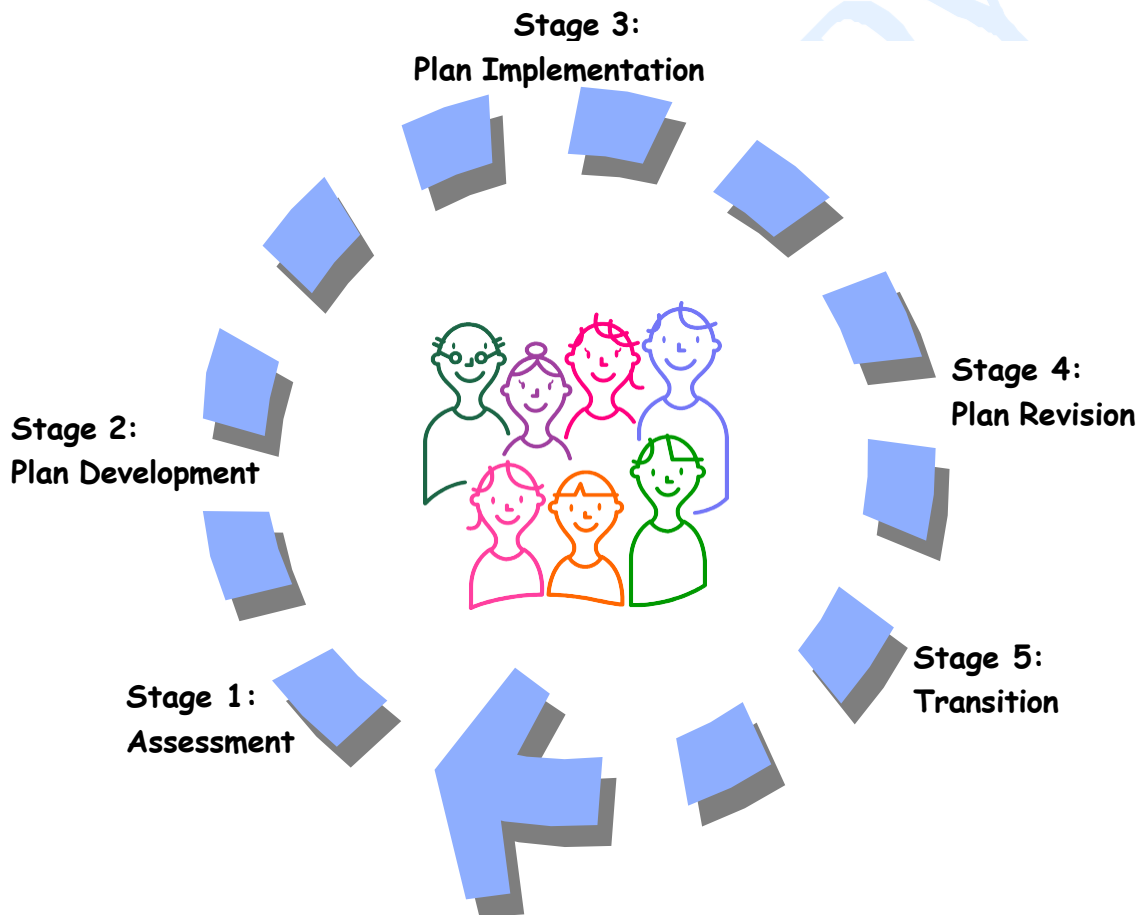
The families of the child or youth with a TBI easily become overwhelmed by the demands of their injured child, their own grief, and a complicated system of care. They can easily feel alone or outnumbered. The care coordinators serve as the families' guide through the jungle of health care, educational, and social service agencies. They are not only Care Coordinators, they are Lifesavers."

Joseph Ackerson, Ph.D.
Pediatric Neuropsychologist
UAB Civitan International Research Center

PASSAGES Conceptual Model



PASSAGES Conceptual Model



**A FAMILY-CENTERED, COMMUNITY-BASED,
CULTURALLY COMPETENT
MODEL OF CARE**

Stage 1: Information Gathering and Assessment



Stage 1: Information Gathering and Assessment

Purpose

The purpose of this stage is to assess the child/youth's strengths and needs within various environments. The care coordinator gathers information essential in planning appropriate interventions with the child and family. During this time the family will tell "their story" and it is the care coordinator's opportunity to support and respect this critical process in gathering information. It is this assessment that provides a comprehensive, culturally sensitive view of the child/youth and family, including strengths and challenges in the following areas: child status, family status, and educational and social environment.

Process

The interview process will be offered in a face-to-face setting. The family is encouraged to choose the site in order to build a trusting relationship and determine the family and child's expectations. The following can be included in this process: medical records, psychological and neuropsychological reports, school records, Early Intervention records, Children's Rehabilitation Service (CRS) records, child and family interviews, and other evaluation results as appropriate. Other issues to be considered are financial and legal status, guardianship/foster care, religious/spiritual beliefs, and cultural influences as well as family and sibling dynamics. Family-centered philosophy is used throughout this process to maintain a compassionate and respectful interaction with the family.

Forms

The following forms are used in this process (see Appendix B):

- * CRS Social History/Financial
- * CRS Medical History
- * CRS Identification of Needs
- * CRS Service Plan and Continuation Page
- * CRS Consent and CRS Civil Rights Compliance Statement
- * CRS Client Family Rights
- * Eligibility Verification
- * TBI Assessment Form
- * Behavioral Checklist

Role of the Care Coordinator

- * Establish rapport with the child/youth and family
- * Explain the CRS community-based services for traumatic brain injury
- * Discuss child/youth and family expectations
- * Conduct initial interview to obtain basic information
- * Assess child/youth's current level of functioning and identify limitations and strengths
- * Provide assistance to family/caregiver in filling out and completing forms
- * Assess structural or other supportive needs
- * Coordinate services with Alabama Head Injury Foundation (as needed)
- * Coordinate services with CRS clinical medical program (as needed)
- * Coordinate services with other providers of medical treatment (Medical Home, Specialty Care providers)
- * Coordinate services with other agencies offering services (as needed)
- * Discuss/refer to All Kids (Children's Health Insurance Program of Alabama) as appropriate

- * Discuss/refer to other resources such as Supplemental Security Income, Alabama's Elderly and Disabled Waiver services through Alabama Public Health, Developmental Disabilities (Alabama Department of Mental Health/Mental Retardation), and Commission on Aging as appropriate.
- * Link between resources (child care/day care, Head Start, educational/classroom, community programs) to promote improved understanding of the impact of TBI on the child/youth and family
- * Provide family education about traumatic brain injury

Role of the Child/Youth (age relevant)

- * Share relevant information throughout the process
- * Share personal concerns and needs
- * Participate in activities to benefit the recovery process

Role of the Family/Caregiver

- * Share all relevant information in this process
- * Encourage, participate, and support recovery process
- * Actively participate in learning about the impact of traumatic brain injury on their child/youth and family

The Real Me

*I am a person kind and sweet,
Who is nice to people that I meet;*

*Who doesn't like darkness,
But loves the day;*

*If you can't tell this is me,
Then look closely and you will see
The Real Me.*

J. A. Parker-17

STAGE 2: Plan Development



STAGE 2: Plan Development

Purpose

An Individualized Service Plan (ISP) is developed to identify the needs of the child/youth and family. The care coordinator utilizes information gathered in the assessment stage to assist in this process. It is important to identify goals and strategies to address the identified needs that promote recovery for both the child/youth and family. The child/youth and family's participation in this process is critical to successfully achieving the goals/outcomes anticipated in the ISP.

Process

Instructions for Development of the Individualized Service Plan

Date:	Need Identified
Need/Concern:	Growth & Development Nutrition Psychosocial Self-help – Independence Mobility Sensory Communication Behavior Medical Recreation
Family:	Transportation Accessible housing Financial Employment Education/Information Support Services Adjustment/Counseling

Action:	Strategies and resources identified to address the assessed needs
Outcome:	Record completion of activity
Date:	Achieved activity

The ISP is a record of the progress of the child/youth and family toward accomplishing the goals. A review of the ISP with the child/youth and family should be made at intervals of six months, or more frequently if appropriate. If the child is being served through Alabama's Early Intervention System, the Individual Family Service Plan (IFSP) can be used in place of the ISP.

Role of the Care Coordinator

- * Continue to establish rapport with the child/youth and family
- * Assess and identify expectations/needs of the child/youth and family
- * Provide support/discussion to prioritize expectations/needs
- * Identify necessary support systems to address expectations/needs and to assure coordination of services
- * Develop timelines for accomplishment of activities to meet goals
- * Make referrals to resources as appropriate
- * Develop Individualized Service Plan document
- * Establish timelines for future reviews

Role of Child/Youth (age relevant)

- * Share relevant information throughout the process
- * Share personal concerns and expectations
- * Participate in the development of the Individualized Service Plan

Role of the Family/Caregiver

- * Share perspective of each family member
- * Identify family strengths and concerns
- * Encourage, participate and support recovery process
- * Participate in the development of the Individualized Service Plan
- * Participate in designing creative solutions to everyday challenges
- * Actively identify persons to support plan implementation

"Teachers treat me differently now. They treat me like a problem child instead of like a child with a problem. There is a big difference."

A child with a traumatic brain injury

STAGE 3: Plan Implementation



STAGE 3: Plan Implementation

Purpose

Plan implementation is critical to achieving the best possible outcomes for the child/youth in the community setting.

Process

The goals established in the Individual Service Plan (ISP) are accomplished through a variety of interventions based on the needs and strengths identified by the child/youth and family. Ideas for possible interventions may be found in the materials listed in the Resource Section. Interventions are discussed for implementation in the following environments:

- * Home
- * Community
- * School

Home Integration

Interventions in the home may include environmental management, family education for coping with behavior changes demonstrated by the child/youth, and/or various strategies to address functional needs. This intervention may include counseling support for high levels of stress, grief, and confusion that the family may experience.

Strategies to enhance the child/youth's functional level may include the following areas:

- (a) Medical management
- (b) Adaptive daily living skills
- (c) Emotional well-being
- (d) Functional cognitive skills
- (e) Academic skills
- (f) Social skills

Role of the TBI Care Coordinator

- * Plan with the family appropriate home-based activities for the child/youth's functional improvement including cognitive, behavioral and physical issues.
- * Educate service providers involved in the plan (ISP)
- * Assist family in monitoring and following through with the child/youth's continued medical care needs
- * Assist family in understanding child/youth's brain injury and the resulting disabilities or secondary conditions
- * Assist families in accessing systems of support
- * Monitor Individualized Service Plan (ISP)
- * Support and motivate the child/youth and family

Community Integration

Community integration includes the child/youth's participation in community-based programs such as faith-based programs (church), child care, scouting activities, school/community sports, ballet/dance classes or any other programs identified by the family. The care coordinator educates the family concerning available community resources. The care coordinator facilitates and

monitors the child/youth's participation in these settings. The care coordinator also works with service providers to provide accommodations, address behavioral issues, and/or other issues relating to traumatic brain injury and successful participation in community activities.

Role of Care Coordinator

- * Coordinate services with community-based programs
- * Support child/youth's attending community activities
- * Educate staff of community-based programs on issues relating to TBI
- * Provide information on ways to be successful advocates
- * Assist families in understanding the child/youth's brain injury (TBI) and functional consequences
- * Assist families in assessing support systems

School Integration

School integration requires collaboration between the family and school personnel. It is most successful when the efforts are worked in a partnership situation with the child/youth's educational success as the goal. The care coordinator serves as a valuable resource to school personnel by providing information about traumatic brain injury and its related disabilities. The care coordinator can provide educators with information that will assist them in the classroom performance of the child/youth with traumatic brain injury. The care coordinator may channel valuable information into the educational setting from specific resources such as hospital team evaluations, neuropsychological reports, follow-up visits, and the family's expectations. All of these have the opportunity to affect the child/youth's academic performance.

Examples of assistance the care coordinator may offer to family/caregiver include:

- * Information about the effect of traumatic brain injury on academic performance
- * Information that will help the family communicate with school personnel
- * Information concerning special education services
- * Information about resources which support families in their efforts to obtain special education services
- * Assistance to the family in securing a letter from their physician stating the child/youth's medical condition, diagnosis, and any restrictions on school activities

Examples of assistance the care coordinator may offer school personnel include:

- * General information about the effect of traumatic brain injury on academic performance
- * Information (with parental or legal guardian consent) of the effect traumatic brain injury has on the child/youth
- * Information (with parental or legal guardian consent) about the consequences of traumatic brain injury on the child/youth's interactions with classmates
- * Resources to assist the school personnel in providing services to the child/youth with traumatic brain injury

Many times school reintegration is from an acute hospital setting or a specialized rehabilitation setting and communication may be in the form of a telephone call or a family contact. The care coordinators offer a unique opportunity to bridge information from those settings and support the family.

The effects of brain injury do not always present themselves visibly and, therefore, the child/youth may not appear to be any different than before the injury. The family may also be coping with a child/youth who looks the same, but no longer acts like the child they knew before the injury. The effects of brain injury are revealed "over time" and it is important to provide information and support early in this reintegration process to offer the most success for the student.

Role of the Care Coordinator

- * Provide information only with the permission of the parent/guardian about their specific child/youth
- * Establish a good working relationship with all involved in serving the child/youth
- * Establish the role of the care coordinator as a resource to the school and family
- * Assist the family in becoming a partner with the school personnel and actively participating in the planning and implementing of services for the child/youth
- * Assist the family in the Individualized Educational Plan (IEP) process
- * Communicate effectively information to school personnel in a manner chosen (written, telephone conversation, team/staff meetings)
- * Understand the administrative structure of the school district, special education coordinator and the specific school the child/youth attends
- * Be knowledgeable concerning special education services, service delivery by school systems, the Americans with Disabilities Act (ADA), and the Rehabilitation Act
- * Participate in Individualized Educational Plan (IEP) when invited by family/legal guardian or caregiver and the school

Role of Child/Youth in Home, Community, and School Settings (age relevant)

- * Participate in recovery activities
- * Share personal concerns and expectations throughout process
- * Cooperate with the Care Coordinator and others in service implementation
- * Participate in the review of the Individualized Service Plan
- * Communicate/share progress in recovery

Role of the Family/Caregiver in Home, Community, and School Settings

- * Actively support recovery efforts
- * Assist the Care Coordinator and other service providers in monitoring the progress toward recovery
- * Participate in the review of the Individualized Service Plan
- * Identify emerging needs to support the recovery efforts
- * Actively participate in identifying and working with other support systems, including school personnel
- * Share family perspective and identify family concerns
- * Participate in educating persons involved about traumatic brain injury
- * Initiate the process of successfully advocating for their child/youth

Stage 4: Plan Revision



Stage 4: Plan Revision

Purpose

Plan revision is necessary in the process of assessment and re-assessment in order to monitor the progress toward identified goals/outcomes.

Process

The goals established in the Individual Service Plan (ISP) are reviewed with the child/youth and family at intervals of six months or more frequently as appropriate. During a six-month period, it is expected that identified strategies complement the identified goals and that there is evidence of progress. The care coordinator contacts the child/youth and family for the purpose of evaluating progress during home visits, school visits, community visits, and phone conversations. During these contacts, additional needs can be identified and added to the ISP. The revision process is an important step in the overall success of care coordination services. Timely communication with the child/youth and family can identify strategies for intervention. Communication is also expected with the other service providers, including the school system.

Role of the Care Coordinator

- * Discuss with the child/youth and family the importance of review of the ISP
- * Educate service providers involved in the review process of the ISP
- * Assist child/youth and family in developing strategies to evaluate/monitor progress

- * Develop a system to contact child/youth and family for the purpose of ISP review
- * Develop a system to contact service providers identified on the ISP for review
- * Support and encourage the child/youth and family in this process

Role of the Child/Youth (age relevant)

- * Actively participate in the ISP review
- * Participate in identifying additional needs and strategies
- * Share continued issues, concerns and expectations
- * Participate in recovery activities
- * Communicate with all system providers concerning the revision

Role of the Child/Youth and Family

- * Participate in the ISP review and update progress
- * Communicate continued concerns and needs
- * Actively participate in identifying additional needs and strategies
- * Encourage and support recovery efforts
- * Identify other areas for support in advocacy efforts
- * Assist in coordination of service needs, including appointments and medical follow-up
- * Communicate with other system providers regarding plan revision and continue advocacy efforts

STAGE 5: Transition and Case Closure



STAGE 5: Transition and Case Closure

Purpose

The purpose of this section is to address the needs of the individual/family as their journey takes the youth into adulthood. This step of the process is designed to ensure that the youth/family are linked to the appropriate resources to assist them in reaching educational, vocational, and/or quality-of-life goals. Further, this stage is designed to develop/enhance skills in the youth and family so that they can continue independently to utilize the **PASSAGES** process in addressing challenges in future transitions.

Process

The ideal goal for the young person with traumatic brain injury is to reach maximum potential for relationships, work, and independence. A major part of that process includes the discussions that help the youth to understand the stage of development and the impact his or her injury has on that development. Planning at each stage is crucial for optimum success for independent living.

Transitions are natural occurrences in a child/youth's life. Some of the transitions may be from hospital to home, home to school, classroom to classroom, or moving to a new school or day care. The ability of the family and youth to navigate each of the early transitions will influence their success as the youth prepares for adulthood. Other elements of smooth transitions will be the presence of support, resources, and information, as well as linkage and coordination of services.

The following key components help in any transition process:

- * Early identification of the special needs of a child/youth with traumatic brain injury
- * Communication with child/youth and family
- * Communication between family and providers of services
- * Appropriate and timely communication between family and school staff
- * Provision of complete and up-to-date information about the child/youth's needs
- * Participation in the planning process to include: Early Intervention transition to educational services, Individual Educational Plan (IEP), 504 planning, and regular classroom accommodations
- * Reassessment of needs and goals for transition
- * Identification of and linkage to resources available to support transition planning
- * Discussion and linkage from Title V programs to Vocational Rehabilitation Service

It is important for the care coordinator to focus on the realistic and obtainable goals at each stage of the child/youth's development. Successful transition through each stage depends on the continuous reassessment of strengths and needs, frequent review of goals, timely access and linkage to resources, and the personal motivation of the child/youth and family. The use of "Bright Futures" guidelines, age-appropriate developmental expectations, neuropsychological assessments, school assessments, medical needs and family involvement are critical to this process. One of the objectives of the Maternal and Child Health Bureau's 2010 Express/10-Year Action Plan is to create community-based service systems for "all youth with special health care needs [so they] will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence."

The following are transition/referral guidelines to Vocational Rehabilitation Services:

- * Caseload review for youth 16 years through 21 years of age
- * Date of injury
- * Current Rancho assessments
- * Current medical status: Needs identified require one or more complex interventions or treatments, frequent and/or unpredictable changes in medical needs
- * Behavioral assessment (use of Behavior Checklist)
- * Discussion/daily activities
- * Youth and family goals
- * Neurological evaluation (current assessment)
- * Experiences (volunteer and work-related)
- * Recreational (community/school) activities
- * Educational and vocational goals

The success of a referral to Vocational Rehabilitation (VR) is linked to the motivation and work readiness of the youth with traumatic brain injury and his or her family. It is also critical for all service providers to be knowledgeable and supportive of these efforts. Communication is key to this process. Open discussion with the youth and family describing realistic steps in preparing for this opportunity is expected. Therefore, discussion and preparation for the referral and eventual transition into VR services begins early in the process of care coordination. The philosophy of building toward job readiness, maximum potential, and independence is shared as a common goal throughout the care coordination process.

Referral/Transition to Vocational Rehabilitation Services

The following activities are steps to successful transition into Vocational Rehabilitation (VR) Services:

- * Review of TBI checklist (see Appendix B)
- * Communication/discussion with youth and family, other service providers, school personnel, and VR counselor
- * Formal referral to Vocational Rehabilitation Services
- * Transfer of pertinent medical/assessment information from the CRS record to VR
- * Coordination of face-to-face interview between youth, family, VR counselor, and the care coordinator
- * Reassessment of interest in VR services (youth and family choice) **
- * Disposition of VR eligibility
- * Communication/discussion of disposition with youth, family, VR counselor, and the care coordinator (face-to-face interview is encouraged)
- * Communication/discussion of service providers for continuation of services
- * Determination for transition and closure to CRS services
- * Communication/discussion with youth and family regarding transition/closure as well as with all relevant service providers
- * Documentation of transition/closure

** A decision of participation in the Vocational Rehabilitation Services can be delayed and the choice of referral/reassessment of services and needs can be offered later.

Referral to Adult Care Programs/Providers

- * Communication/discussion with youth and family regarding change in benefits (This information sharing begins at 19 years of age.)
- * Discussion/referral to adult health care providers and other adult community programs/providers
- * Review of youth and family needs/plan for addressing those needs
- * Discussion and preparation for transition from care coordination services to community program/providers
- * Coordination of face-to-face interview/meeting with adult community program/providers
- * Communication/discussion of transition from care coordination services to adult community programs/providers (letter to family)

The family/guardian's role in the transitions of a child/youth cannot be overstated. Their motivation and dreams greatly influence the success of all transition periods in the child/youth's life. As professionals develop strategies and organize information for the child/youth's new stage, the family often struggles with the "new" transition they face: the new day-care, changing schools, classroom assignments, or graduation. Will their child/youth make new friends or keep some of his old friends? Will he feel accepted? Will he be successful? Will he be okay?

Role of the Care Coordinator

- * Communicate with youth and family information necessary for a successful transition into adult services, including plans for vocational and educational goals
- * Discuss and identify adult care programs/providers
- * Coordinate meetings with adult system providers for all identified transition needs

- * Discuss and support referrals for additional system supports
- * Re-assess individualized needs and expectations throughout the transition process

Role of the Youth

- * Communicate personal concerns and expectations throughout the process
- * Actively advocate for own needs
- * Participate in the identification of additional needs with other service providers
- * Be assertive and ask questions
- * Participate in the planning process for transition, including development of vocational, educational and independence goals

Role of the Family/Caregiver

- * Support opportunities to encourage appropriate transitions to all aspects of adult life, including health care, education, work and independence
- * Discuss openly transition efforts
- * Communicate family needs and perspective throughout the process
- * Be positive and reassuring to their youth
- * Be assertive and ask questions
- * Seek opportunities to include creative strategies to everyday challenges
- * Participate in identifying transition needs during the development/revision of the Individualized Service Plan
- * Communicate with service systems during this effort
- * Support their youth's self advocacy efforts
- * Encourage their child/youth to be independent
- * Discuss and follow-up on referrals and linkage to other service systems

PASSAGES is a service model that encourages many partnerships for families. The purpose of this model is to empower children/youth with traumatic brain injury and their families to successfully access opportunities that enhance their world.

*"Alone we can do so little,
Together we can do so much."*

Helen Keller

REFERENCES

American Academy of Pediatrics. (2000, January 20). Improving care for children with special health care needs. AAP News Release.

Brown, T., Lake, K., & Varela, F. (2002). Meeting the needs of families: Critical elements of comprehensive care coordination in Title V children with special health care needs programs (DHHS Publication No. MCHN126). Washington, DC: The Association of the Maternal and Child Health Programs.

DO NOT COPY

Appendix A: Pre-Discharge Model of Care



Appendix B: Forms



Appendix C: Key Elements of Family-Centered Care



The Key Elements of Family-Centered Care

- * Incorporating into policy and practice the recognition that the family is the constant in the child's life, while the service systems and support personnel within those systems fluctuate.
- * Facilitating family/professional collaboration at all levels of hospital, home, and community care:
 - care of an individual child;
 - program development, implementation, evaluation, and evolution; and,
 - policy formation.
- * Exchanging complete and unbiased information between families and professionals in a supportive manner at all times.
- * Incorporating into policy and practice the recognition and honoring of cultural diversity, strengths, and individuality within and across all families, including ethnic, racial, spiritual, economic, educational and geographic diversity.
- * Recognizing and respecting different methods of coping and implementing comprehensive policies and programs that provide developmental, educational, emotional, environmental, and financial supports to meet the diverse needs of families.
- * Encouraging and facilitating family-to-family support and networking.
- * Ensuring that hospital, home, and community service and support systems for children needing specialized health and developmental care and their families are flexible, accessible, and comprehensive in responding to diverse family-identified needs.
- * Appreciating families as families and children as children, recognizing that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services and support.

Shelton, T.L. & Stepanek, J.S. (1994). Family-centered care for children needing specialized health and developmental services. Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, Maryland 20814, 301/654-6549.