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ABSTRACT

A meeting of professional experts in pediatric traumatic brain injury (TBI) focused on gathering current expert opinion regarding assistance to families with a child having such an injury. Quantitative data from an ethnographic survey of 214 parents on the effects of TBI on the family is summarized. Then, normalization for families of TBI children is addressed including normalization or social role valorization and provision of services versus supports. A discussion of improving medical services for the family, by James Wasco, is summarized next, followed by an account of a talk on improving rehabilitation services, by Ellen Lehr, who offers recommendations concerning development of educational material for families, training for rehabilitation professionals, and the development of continuity in services. Finally, Janet Williams looks at the family and the community and offers such recommendations as "establish a facilitator of integration" and "create Individualized Family Service Plans for all families of children with TBI." Agreement by participants that case management needs to be expanded to provide more direct help to families is noted. A final section on historical perspectives compares the medical and residualist models of case management and recommends replacement of the "case manager" role with the "resource specialist" role. (DB)

Model Family Professional Partnerships for Interventions in Children with Traumatic Brain Injury

by Betty Pieper, B.S., R.N.,C. and George Singer, Ph.D.

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Introduction:

This paper summarizes a nominal conference of invited professional experts in pediatric traumatic brain injury who gathered under the sponsorship of the New York State Head Injury Association in Albany, New York, on November 9, 1990. The Conference was funded by a grant from the United States Department of Education, National Institute on Disability and Rehabilitation Research. The purpose of the meeting was to gather current expert opinion regarding family focused assistance for families in which a child experiences a traumatic brain injury.

A commentary, "Rethinking Family Assistance" discusses the historical underpinnings of case management and proposes re-forming case management concepts and practice. A new role for professionals and families which synthesizes the recommendations of the conferees is an important proposed theoretical development with major implications for family-professional interventions and for public policy.

Grant Proposal Summary: The Model Family-Professional Partnership research project funded by NIDRR from 1988-1991 has two components: one, a survey approach using a Family Questionnaire consisting of many well-established and original instruments measuring family stress, family resources, coping and adaptability, and, two, a qualitative component consisting of consensus meetings with parent caregivers and later with a group of selected professionals responding to the concerns raised by parents. The results of the parent nominal group process conference and preliminary results of the family surveys have been presented in a paper entitled "You Can't Imagine Unless You've Been There Yourself" by George Singer, Ph.D. The experts who gathered in Albany for a consensus conference reviewed a draft of this report prior to their arrivals.

The Professional Consensus Conference: In deciding how to structure the professional consensus conference, it was also necessary to decide what the overriding themes of the parent conference were and to simplify the report. Dr. George Singer and Betty Pieper met for a full day in October 1990 to discuss primary parental concerns and to determine a process and structure for the day. Subsequently, Dr. Susan Cox, Principal Investigator, Dr. Singer and Ms. Pieper agreed upon a participant list which seemed matched to parental experience and concern. Each participant was asked to read the parent conference report and received information from Dr. Singer ahead of the actual meeting which was held in Albany, N.Y., on November 9, 1990.

Conference Structure: It was decided to create a balance between planned presentations and discussion which would then produce concensus recommendations. In order to facilitate the outcome of actual recommendations, each of the presenters was asked to bring specific recommendations. Some participants were designated as reactors to specific presentations, but all participants were requested to offer comments and enjoin the discussion following the presentations. The goal would be to examine all recommendations at the end of the day and to add, delete, combine or rework the recommendations so that they represented the work of the conference. Each participant was asked to read the parent conference report before the meeting.

Conference Themes: The day-long discussion was built around an overriding question and subthemes. The primary question chosen was:

• How can family focus and strength be preserved and how can the alienation process (the painful "shunting aside") which parents and other primary caregivers feel, almost from the moment of injury, be prevented.

In assessing parent stressors, it was also apparent that the quality of care a child is receiving -- or even the parent's perception of that care -- is critical. There is a great need for parents and other primary caregivers to feel that "everything possible" is being done for the child in order to give the child the "best chance" at recovery. Therefore, the subtheme for the day was formulated in these questions:

• How can professional competence in the delivery of services (emergency medical, rehabilitation, school, etc.) be accompanied by emotional support/caring and on-going information about TBI generally and the child specifically? How can clinical and program competence be combined with planning and coordination of services so that adequate resources are made available which will result in quality services which feature consumer choice?

Participant Selection: Professional participants were selected not only for their knowledge and experience in the field of traumatic brain injury but also for their respect of parents and their personal commitment to change for injured individuals and their families. (See attached Participant List.) Four individuals were selected to give presentations. Since there was an implicit recognition throughout the parent meeting that values are an important part of service design and delivery, it was decided to make this explicit by including a presentation on values and family perspectives near the beginning of the conference.

Agenda: Dr. Susan Cox, Principal Investigator and Executive Director of the NYSHIA, welcomed participants and gave an overview of the total grant. Participants introduced themselves as had previously been requested by telling something about what brought them to their personal commitment to people who had sustained traumatic brain injury and their families. In addition to more traditional vitae information, they also commented on personal frustrations and hopes as well as systems' barriers and opportunities as they view the field today.

Dr. George Singer acted as facilitator for the day. He began by presenting an "Overview of the Colloquium" followed by comments and overheads which reviewed the preliminary results prepared by Mt. Sinai of the NYSHIA Family Questionnaire and other recent research. A summary of this presentation and the others which follow are annotated by the authors of this report.

I. Review of Recent Data on the Effects of TBI on the Family by George Singer, Ph.D.

Dr. Singer presented the result of an ethnographic study of parents of children with TBI. It utilized the transcript from the NYSHIA parent nominal group conference as one major source of data along with extensive interviews of parents. He explained that qualitative methods allow the researcher to capture information which emerges directly from the experience and expressions of people as they see their issues and as they choose to tell them. Dr. Singer explained his choice of

the ethnographic method as a way to gather and understand the stories of people so that their issues may be used to individualize and personalize services for them as well as to inform social policy and planning.

In order to "triangulate" the findings from this ethnographic study, Dr. Singer first presented corroborative evidence from the NYSHIA family survey study. In commenting on the ways that the findings from the two aspects of the research seem similar, Dr. Singer discussed some of the data from the Family Questionnaire survey. He noted that of the 203 respondents answering the question, 88% stated that at least one member of the family had to cut back on his or her paid work schedule. This has obvious implications for economic consequence as well as possibly creating disturbances in how one is viewed by others (social role), self-esteem, life satisfaction, etc. At the time of the survey, 38% of the respondents noted that job related changes were still in effect.

Another potential indicator of stressful experiences is revealed in data on hospitalization. Almost a third (31%) of the respondents answering (228) were involved with acute care hospitalizations of more than 12 weeks and an additional 51% were involved in acute care hospitalizations of more than 3 weeks. Thus, in a day and age in which people are routinely released from open heart surgery within a week, fully 82% of the respondents were coping with hospitalizations of their children which were over 3 weeks in duration.

Of the 129 respondents who answered regarding rehabilitation, almost half (45%) were involved in outpatient rehabilitation after 13 months. It might be expected that these people experienced problems often associated with outpatient appointments, namely: difficulties with funding sources, difficulties in communicating and interacting with professionals, difficulties scheduling, the need for additional paperwork and bookkeeping, and difficulties with transportation. In our NYSHIA experience, significant numbers of people have reported difficulty working due to "appointments" as distinct from other care related activities. Another 44% experienced out patient rehabilitation for more than 1 month.

The survey study also suggested that the injury brought other important changes to the individual's lifestyle. The decrease in social contacts and pleasurable activities following a child's injury was also significant. Although various categories of activities differ in the percentage of pre-injury and post-injury participation, the direction is relentlessly toward social isolation. In other words, although contacts decrease with relatives, contacts with friends drop more; the experiences that drop most are those more connected to the broader community such as going to shows, concerts, parties and sporting events.

Fifty two percent (52%) of 214 respondents reported needing assistance in caring for their injured family member and 44% noted that they paid for assistance. In answering a question on unmet needs, 50% identified housekeeping help as needed. A least one out of three also stated that they needed: resources for the child, resources for their family (42%), for a friend or someone trusted to understand child care, relief from responsibility, to discuss feelings, and to be reassured about their negative feelings. Many noted significant doubts for the future (37%) and a need to prepare for the worst (38%) as well. Dr. Singer stated that this information is congruent with other studies which indicate that it may be the day to day hassles, the social isolation, and the decreased resources that create stress and depression in families.

Dr. Singer noted that of the 59 people who responded to the question as to whether or not they had separated or divorced after the child's injury, 48% responded positively. Of those answering the question calling for a judgment as to whether or not the separation or divorce was related to the

injury (43), a surprising 74% said their separation or divorce was not related. Dr. Singer also requested that as recommendations or interventions were set forth throughout the day, participants should ask, "How would this change for a lower economic status family and how would this change for a minority family?"

Dr. Singer followed this review of the quantitative study with quotations from the parent nominal group conference and his ethnographic interviews.

II. Normalization for Families or When a Child Becomes 'Special,' Special Supports are Needed to Keep the Family 'Ordinary'" by Betty Pieper

Participants were asked to list some of the commonly agreed upon values in society: beauty, health, safety, wealth, power, competence, control, freedom, personal rights, independence, etc. RELATIONSHIPS was put forth by a participant and the group agreed that stable, trusted and intimate relationships are almost universally valued elements of life. Ironically such relationships are likely to be lost to the person with traumatic head injury and to the family caregivers.

Normalization or Social Role Valorization: The principle of normalization or social role valorization was presented through the following definitions: 1.) culturally valued means are used to obtain life conditions for a person which are at least as good as the average citizen's life conditions, or 2.) ABC: Assess/Address the Behaviors with a view to what is Culturally Correct or Culturally in Character and provide resources to bring congruency. Ms. Pieper stressed that the behaviors which need changing may be in the individual, in other individuals, and/or in the community and/or the broad society. Normalization is time and culture bound. What is typical or valued today may not be typical or valued 10 years from now and may not be valued in a different place on earth at the present time.

Above all, it is important to note that normalization is not "cosmetic." It does not mean that if we dress a person in a certain way, "everything will be fine" or that deficits will magically disappear. Normalization acknowledges that carefully chosen professional contacts and programs can promote the development of an individual's personal competence, perceived social value, and feelings of self worth. She gave examples of negative image making through deviancy juxtapositions, language and labeling, segregation, paternalism, and through attire, activities and personal possessions which are not age-appropriate.

Services versus Supports: Ms. Pieper noted that as a culture we not only value the individual, but we also scrutinize, judge and "assess" individuals extensively. We create, support, and designate many different kinds of professionals and paraprofessionals to become "helpers" in order to formally address individual deficits and needs. We also create many different kinds of services and then attempt to tie them together through complex systems and bureaucracies. Ironically, this approach which is originally based *on the individual* tends at times to confuse and "bury" the individual and the family.

Ms. Pieper noted that sometimes we offer services when supports would be more effective; services and supports are distinctly different. She describes services as likely to be special, scheduled, structured, staffed, esoteric, segregated and formal. They also tend to be costly. Services are usually triggered by assessment of an individual and the identification of specific need or deficit. Even when the need to be filled is common within the general population, it becomes

different and special when offered to labeled people and their families. Thus, babysitting becomes "respite" and respite becomes "in-home respite," "out-of-home respite," and "free standing respite." Specialty licensures become likely and bricks and mortar is not far behind.

Supports, on the other hand, tend to be natural, unpaid, flexible, informal, at-hand, generic, bartered or exchanged and under the direct control of the consumer. Further, the consumer often trains the person in any idiosyncracies and expects full compliance and satisfaction instead of special licensure. Examples of supports which are (or should be, in Ms. Pieper's view) generic are: universal health insurance, family leave for caregivers, childcare at any hour of the day or night for family emergencies, sick child care, etc. When special "places" and bricks and mortar are needed, they should be designed for all citizens (ie, neighborhood and family centers). The difference between services and supports is often the difference between grandma or the neighbor and a certified home health care aide from a certified home health agency which are, of course, available only to labelled individuals.

Marc Brandt, Executive Director of the New York State Association for Retarded Children, delivered an extraordinary address at the Association's "In Support of Families Conference" on July 28, 1990. Although the NYSARC is one of the largest human service providers in the state, Mr. Brandt stated that, "Perhaps the best way to support families is not to use providers at all. Bypass providers; give money directly to families and let them decide how best to use it."

Ms. Pieper noted that herein we have a dilemma. Although most people would not say overtly that having a child with a disability at birth or through injury is the parent's fault and therefore should penalize a family unduly, the reality is that there is great and deep resistance to "giving money" to families directly--or even allowing them to keep more of their own through appropriate tax credits for injury related expenses which are atypical. Policymakers frequently ask, "What will they do with it? How will we monitor against abuse?"

Even when we understand clearly that there is great waste and abuse within large systems, there seems to be a more rigid standard for individuals and families. Ms. Pieper believes that this may stem from various subconscious sources, but it is real and needs to be brought to the surface and faced. *She advocates that as an overriding principle to guide us we accept the premise that each individual and family should have the expectation of a life which is similar to what they would have reasonably expected had the injury not occurred.* Costs, in terms of money, time, and psychic energy should be typical and when they become extraordinary, supports (which she calls social insurance) should kick in.

Ms. Pieper believes that if <u>every individual and family</u> (not just those who have developmental disabilities or traumatic brain injury) knew they could benefit from a safety net of social supports, the "them" and "us" undercurrent might disappear. If supports would serve as insurance policies for everyone, everyone might join in calling for change.

Ms. Pieper read some principles decided on by families throughout the state at the In Support of Families Conference, July 1990. She felt that the principles are largely congruent with feelings expressed by the parents of children who had suffered head injuries.

- All children, regardless of disability, belong with families and need enduring relationships with adults.

- Families should receive the support necessary to maintain their children at home.

- Family supports should build on existing social networks and natural sources of support.
- Family supports should maximize the family's control over the services and supports they receive.
- Family support services should encourage the integration of children with disabilities into the community.

III. Improving Medical Services for the Family by James Wasco, M.D.

Dr. Wasco stated that as a young doctor working in trauma medicine, he often wondered what happened to his patients, and, in fact, was fortunate enough to be able to go across the street to a rehabilitation facility to follow through with this. This initial interest has grown and he is now actively involved in care at all levels and feels that communication between people and programs is as important as clinical competence.

Dr. Wasco began with insight into the "Golden Hour" after injury in which excellent, aggressive emergency medical care is thought to make a real difference in outcome. He wove substantive accepted medical practice (ie, using a spinal board to immobilize victims of head injury since there may be a spinal cord injury as well) with the associated stressors on families throughout his presentation. At this point, he noted, the family feels almost as if a larceny has been committed; not only has their son or daughter been hurt, but the person has been snatched away in an ambulance by people they do not know. Dr. Wasco's perceptions of what the family is feeling and what creates stress reflected what staff of the New York State Head Injury Association have heard over and over in talking to families.

He summarized by saying that in the emergency and acute treatment phases the main problems for families seem to be: the unknown regarding the person's condition and prognosis, the waiting and isolation, and the unfamiliarity of almost everything. Families are thrust into a strange world where the physical surroundings are unfamiliar, the language and terminology are unfamiliar, the protocols are unfamiliar and they do not recognize the various roles of health care personnel--who does what, who knows what, and whom to approach for what. Sometimes the family cannot recognize their own child because of facial swelling, bruises or lacerations which are additional to the various lines and equipment to which he is attached.

Dr. Wasco's recommendations with some amplification by the group are summarized below:

1.) Increase communications with families. There need to be ways that professionals who have direct knowledge of the child's condition can talk to the parents in a timely fashion. Because the professional cannot and should not make a long term prognosis, this does not mean that he or she does not need to make time to talk to families. While all team members should learn skills in talking to parents, it is helpful to have one point of responsibility in someone who can tell the parents the truth in a timely and caring fashion. Practical mechanisms to support communication to loved ones who are not able to visit might be the provision of free long distance calls for families to talk to those "at home."

2.) Build bridges from trauma to rehab to the community. Encourage specialists to "know and go" across discipline and across time. Many people have spoken to the need to have specialists be more knowledgeable about other disciplines and to act through true interdisciplinary teams rather than in parallel through multidisciplinary "teams." Dr. Wasco explained that it is equally important for first responders to know what happens in the emergency room and for trauma teams to know what happens on the hospital floors and in rehabilitation settings. Medical personnel should know what kinds of problems and difficulties their former patients experience (as well as share in achievements and successful adaptations) in reentering the real world.

In response to this proposal, Dr. Ellen Lehr described her work in hospital settings in which interdisciplinary teams made rounds as teams to patients at each phase of treatment and rehabilitation.

3.) Promote research into how short term acute care impacts long term outcomes. Dr. Wasco pointed out that there is as of yet little scientific information available regarding the impact of various emergency department and intensive care unit practices on long term outcomes.

4.) Dr. Wasco's fourth recommendation concerned "minor" or "mild" traumatic brain injury. He called for widespread education of medical personnel regarding the potential long term impact of head trauma that does not necessarily involve loss of consciousness or coma. Training of emergency service personnel should include the potential for long term sequelae from "minor head injury." Too often people are released from the hospital with only the warning of acute and dramatic neurological change such as is expected from subdural hematoma. They are not informed of other potentially debilitating though less dramatic problems which may arise. There is also a need to have appropriate equipment available; xrays are not adequate and yet are still commonly used in isolation. Individuals may need to be asked to return, given appropriate referrals and follow up.

Other personnel need to be educated as to the potential problems from minor head injury as well since often the injury is not considered serious enough for emergency treatment. Physicians, office nurses, school personnel (nurses, teachers, coaches, driver education staff, etc.) and others such as Little League coaches, Scout leaders, etc., also need to be educated to the possible consequences of "minor head injury" so that they will respond in a more systematized and serious way.

The ensuing discussion period generally reinforced and amplified the recommendations. Some of the problems go beyond simple lack of training, time or caring. The concept of a need for the "rationing" of health care and for triage which selects those deemed most likely to benefit or those most valued is uncomfortable in practice. One of the barriers to quality care for all is that we as a society seem to have little sense of social responsibility for each other; we value independence and competition more than interdependence and cooperation. We also seem to respond best to high visibility <u>but short term crises.</u> Traumatic brain injury (except in its Hollywood version) does not fit this category. It was felt that we need to find a way to have people consciously understand the "costs" of valuing technology and of saving lives with extraordinary measures, namely that we then have a subsequent responsibility to the person who has been the recipient of our good intentions.

IV. Improving Rehabilitation Services for the Family by Ellen Lehr, Ph.D.

Dr. Lehr placed 3 recommendations before the group and used these as the basis for her presentation. She chose the following categories:

- development of educational material for families,
- training for rehabilitation professionals, and
- the development of continuity in services.

The following represents an annotated version of her outline with additions from the group incorporated.

1.) Train families as individuals and as units. One aspect of this is the development of educational materials for families. All material should be clearly written, and, if appropriate, attractively illustrated. Material needs to be developed for parents and for the brothers and sisters of children who have been injured. The information should be a survival kit of the most basic kind: the Rancho Scale, common medical terminology, etc.

Parents should "speak to other parents"; some of this can be done through print media or video. Material should be made available which will help parents to understand that they are not alone though the sharing of first hand accounts. Personal accounts could be organized in chronological order by the time of injury, age of the child and severity of the injury.

Parents also need "How to" manuals, including how the family member can develop skill as case manager for the child, how to deal with schools, and how to manage challenging behaviors in the child, how to manage changes within the family's relationships, how to take care of themselves, and how to handle their own stress in positive ways.

2.) Train rehabilitation professionals in working with families: The team should understand the "family component of TBI natural history." They should understand how parents frequently feel at various times without forcing parents into a molds or stages. They need to understand the kinds of stresses which parents commonly experience, including the need to have a consistent and knowledgeable source of information about their child.

The team members should be taught interactional techniques to work with families under stress. The team should understand the importance of incorporating the family into treatment decisions, treatment routines and planning conferences. Training should include the importance of support groups for the family during rehabilitation and within the rehabilitation setting. Professionals need to learn how to take care of themselves and their colleagues by identifying and actively managing their own stress.

3.) Develop/improve continuity in services: clinical case management is crucial. Dr. Lehr notes that an advantage of having one person in this role from in-patient through out-patient and into community services is that the professional is then in a better position to evaluate the child's progress over time as well as providing the family with continuity. Just as rehabilitation professionals must learn to work with parents and appropriate family members immediately after the child's injury, they (rehabilitation professionals) must also learn to work with community based service personnel and services. Often, as in the case of the school, this may need to be initiated from the rehabilitation team. Such collaboration assumes the existence of an adequate number of quality outpatient and educational services which are accessible by families, and this is often not the case and presents another challenge in brokering services.

Parents and family members require information, education, communication and emotional support within the rehabilitation setting and this needs to continue through the out-patient period. One way

to plan for this continuation and the continued working relationship of the parent and professional is to sponsor support groups which are "co-facilitated" by a parent and a professional. In this way, parents can learn interactive techniques and professionals can gain insight into the real lives of the people they seek to assist.

V. The Family and the Community by Janet Williams, M.S.W.

Ms. Williams reported on her studies in Europe. She visited with families of children who had been traumatically brain injured. Through close contact, she sought to better understand their daily lives, the challenges they faced and the resources which were available to them. In some European countries a person is assigned a social worker by date of birth and that person remains the same over time. The social worker knows the person well and is responsible for helping the person navigate through life's crises. She felt that a similar approach might be useful in the United States.

In the U.S. at present it is most often parents who are left to find appropriate services for their children. Few parents will have the clinical and program backgrounds to know what kinds of interventions are needed, let alone what is available or how to broker the fragmented "system" of services which characterizes an entrepreneurial country. Therefore, some form of case management has been widely heralded as necessary and is often referred to as the "glue" which holds many components of our service system together.

Some families prefer to undertake, develop and sustain this case management role themselves, often because they do not feel that anyone else will be as strong an advocate for their child and for the family unit. Other families, perhaps a majority, would prefer not to have this task which can become a fulltime job which consumes their time and energies. The "costs" of caregiving and case management are often measured in the loss of personal freedom, loss of job or career advancement, loss of economic security, and severely constricted personal relationships.

Ms. Williams made the following recommendations which have been annotated.

1.) Establish a facilitator of integration. This person's primary responsibilities are to promote and balance individual growth and family unity. This person does not do traditional case management but rather facilitates linkages to resources. The Facilitator would be assigned immediately after a reported injury or upon diagnosis. The person would be consistent over time and would offer ongoing support to families acting as an advocate, counselor and troubleshooter. The Facilitator is regionally based so that (s)he knows the formal and informal resources available in each region.

It was noted that European countries have a different sense of community than we in the United States; a model which works well there might not meet with success here. Participants felt optimistic about the acceptance of integration as a direction and guiding principle. There was also a feeling that the current interest in case management in our country might be able to be used to strategic advantage in creating a model which would test the Facilitator of Integration approach.

2.) Create Individualized Family Service Plans (IFSPs) for all families of children and youth with TBI: These plans might be similar to the IFSPs which are required through Part H of P.L. 99-457. Plans would have a family centered focus. The plans would be written by the family and the Facilitator of Integration and would be designed to develop and support "marathon skills." The plans are rewritten over time and at developmental milestones or life transitions.

Ms. Williams talked about "marathon skills" as developed by Dr. Ann Turnbull at the Beach Center for Families and Disability in Kansas. An annotated list follows:

- Be able to meet basic needs -- food, clothing, shelter, safety and relative security must be available.

- Know yourself and your family -- the styles and strengths as well as the needs of individuals and the family unit are important to identify, to "know" and to accept. Decision-making, communication, and daily living become easier with this insight.

- Love your child unconditionally -- for himself/herself as (s)he exists each day not as (s)he might become "if only" (s)he could walk or talk or remember better.

- Establish relationships -- the disruption caused by prolonged out of home treatment and rehabilitation presently decrease the likelihood of maintaining existing relationships. Attention needs to be given to ways to maintain desired relationships as well as to create new relationships in the community which are not limited to disability related experiences.

- Experience and benefit from emotions--people need to learn to experience and to own their natural responses. Too often designated personnel (the social worker or psychologist) are charged with "listening" when in reality everyone involved with the child and family needs to be charged with listening and respecting what families feel. Family members need encouragement and support in expressing honest emotions and not what they think will please "experts."

- Anticipate the future and learn transitional planning--while specialty components are important (the ways families are "different" as a result of the injury), most planning can be the same as for other people. It is important not to let the part destroy the whole.

- Establish balance -- current practices feature a pressure for parental involvement and a necessity for a large investment of time and energy; the family needs to insist upon a balance and to learn to assert their right to a balanced life without guilt.

- Learn to negotiate systems -- there is a need for more discussion in this area. To what extent should a family be required to "train" in the skills ordinarily developed by social workers and case managers? What are the crucial kinds of information they need to monitor their own services and to make intelligent and powerful choices without assuming the data base or the responsibilities of a professional role for which they may have little aptitude or liking?

Comprehensive Family Support Strategies: Ms. Williams noted some kinds of supports which are regarded as helpful to families. Among these are family to family networks, self help groups, family help lines for information, referral or counseling, and advocacy training for family members. Futures planning in which the injured child and the family identify and learn to use community and social support networks, is also important.

Related Interventions or Models: One family known to the NYSHIA consists of two parents who are knowledgeable professionals. They found that seeking therapies, educational services, and caregivers was so time consuming and emotionally draining that their careers were jeopardized and the relationships within their family and in the community would be likely to suffer. Yet they were unwilling to compromise on the quality and quantity of services their son and their family needed. They decided that they required someone to do case management for them. "We wanted someone loyal to us and to our son. We did not want a cost containment specialist who is serving an insurance company's interests or a government's interests rather than the interests of our son and our family." They were able to use some no-fault insurance money to hire and train a case manager to serve their interests.

The person hired for this assistance was not a clinical case manager as we know that role. Her role was probably more like the Facilitator of Integration especially if the role is conceived as respectful of specialization and clinical expertise within community-based, integrated and common to all settings. From talking to families, it is proposed that some desirable characteristics of the case manager or Facilitator should be:

- independence--the case manager or Facilitator should not have any relationship with a provider or funder of goods or services which would be perceived as a conflict of interests.
- chosen and directed by the consumer--the case manager or Facilitator works for the family and on behalf of the family. Ideally the family should be able to change to another individual if they so choose.
- regionally based and broadly knowledgeable of both specialized services and generic supports and services.
- strongly biased toward integrated services and both creative and knowledgeable regarding techniques for bringing beneficial specialty expertise into common settings without destroying the generic quality.
- empowered to "create" supports which are needed.

Rethinking Family Assistance: Reforming Casemanagement

At the request of the participants at the professional conference, Dr. Singer prepared a statement regarding trends in case management services for families of children with traumatic brain injury.

A serious effort to meet the needs of families as part of the care and rehabilitation of children who experience traumatic brain injury will require a considerable rethinking of the way that supports for families are organized and delivered. *All of the experts at the conference concurred that the current fragmented service system is incomplete and does not meet the needs of families. All seemed agreed that one important remedy to the exclusion and shunting aside of families appears to be the creation of some form of personal assistance that represents an evolution of the role of case manager.*

As suggested by the presenters at this conference such a person would serve several functions including:

a) providing timely information to family members throughout the process of acute care, rehabilitation, and reintegration,
b) assisting the family to maintain and strengthen informal sources of support,
c) assisting the family to identify and meet needs,
d) helping with dealing with medical and fiscal bureaucracies,
e) providing continuity as the child moves through the phases of treatment and reintegration, and
f) facilitating social integration of the child.

<u>This kind of role represents a considerable divergence from traditional medical and social work conceptions of service delivery.</u>

Historical Perspectives

The Medical Model: There are two historical influences that are shaping the current fragmented service system as described by the conference participants. The first is the medical model with its emphasis on the treatment of acute biophysical conditions. Historically, medical treatment has been designed to cure acute short term illness. The patient in this model is viewed almost solely as a biological entity with problematic functioning of various organic systems. Treatment is designed to be intensive, short term in duration, and intended to result in a cure.

In the case of traumatic brain injury in children, the results of severe trauma are likely to last a lifetime and to require on-going care and rehabilitation. While the early phases of treatment in the emergency room and ICU require the methods of acute care, they do not prepare families for the long term impact of the trauma. The patient is viewed almost solely to be the injured child, and family members are often shunted aside as impediments to technical care rather than as allies and as the recipients of injury.

The traditional acute care medical model does not view the child as part of a complex social system which is as much a determinant of his health and well being as the status of his physical organism. However, in the long run the child's rehabilitation and reintegration into society depends as much on his or her family as on the nature of brain lesions and tissue damage. In the traditional medical model the relevant knowledge is highly technical and only accessible to a few who have been highly trained. The kinds of every day understandings and common discourse that prevail in families are largely irrelevant in this world of technical knowledge and highly refined expertise.

The Residualist Model: A second historical influence also has a pervasive impact on the design of traditional case management. It is the social welfare tradition that Maroney (1986) has called "residualism." The residualist tradition descends from the English Poor Laws which set the precedent and tone for community care for vulnerable people from the 1600's until World War II in England. In many ways the tradition continues to dominate contemporary social policy in the U.S.

In the residualist tradition only the deserving poor are worthy of public assistance. That is, assistance should be given only to a few who are in the most dire of circumstances. In this tradition, it is important to establish that a person is eligible for public assistance lest an unworthy person become a kind of social parasite. The process of designating who is worthy and who is unworthy becomes very important in this tradition. As the notion of the expert became increasingly prominent in the 20th century, this job of sorting out the eligible from the ineligible was assigned to certain groups of experts, usually social workers. One of the tenets of the residualist tradition is that people should receive community help only after they have already failed to perform basic social functions. *This means that families who are struggling, but have not failed are ineligible for help. By definition, help and crisis management become synonymous.* Preventive and promotional interventions do not fit well in this model.

In the residualist tradition power is vested in the helper. The helpee is, by definition, assumed to have failed at key social tasks - otherwise he would not be deserving of help. In this model stigma is attached to the receipt of assistance. A review of the literature on case management suggests that it has been most widely used with populations who are disadvantaged and often viewed as unable to act upon their own behalf (Dunst and Trivette, 1989). Thus, casemanagement has been widely used with chronically mentally ill persons, developmentally disabled persons, health impaired children, and retarded or otherwise handicapped children. Recently, case management has been extended to the parents and families of these individuals. However, the transfer of procedures that are aimed at relatively powerless individuals to families is not necessarily desirable. <u>The models of casemanagement that are prevalent in the recent social work literature may not represent a sufficient break with the medical and residualist traditions to meet the needs of families of children with traumatic brain injury.</u>

New Goals and New Roles for Helper and Family: Based upon the suggestions of the conference participants, new models of case management for families of children with traumatic brain injury would include several philosophical and practical innovations. First, a different terminology would be used because "case manager" implies that families are loci of problems that are to be externally operated upon by a helper. A term like "TBI Resource and Information Specialist" might more closely approximate the function of this new role that is emerging in some model programs such as the FACTS program (Family Advocacy, Counseling, and Training Services) provided by the New York State Head Injury Association.

The resource specialist would provide information to family members at all phases of treatment and rehabilitation. Information would be given in language and circumstances that would favor its reception. It would include sensitive translations of medical diagnoses, information on typical course of treatment and prognosis, and information regarding resources.

The resource specialist would also be highly skilled at assessing family needs and in helping families to set goals around meeting these needs. Family needs would be viewed as highly fluid, changing at different phases of treatment and rehabilitation. For example, needs for basic maintenance of family caregiving routines may dominant while an injured child is in intensive care, whereas later, parents and siblings may need information and contact with other families in order to adjust to the changes in the child and in the family dynamics. At a still later date, families may need help with behavior management and linkage to public school programs. Thus a skilled family specialist would know how to continuously assess the moving target of family needs and how to assist families to meet them.

In the field of developmental disabilities there has been a recent emphasis on methods of helping that empower and enable families. This language of empowerment would appear to be useful in the field of head injury also. *The essence is that an effective helper is one who assists family members to find their own strengths, learn new skills, and call upon informal networks to solve their own problems.* When external help from professionals or helping agencies is required, it is delivered in such a way that the family ultimately attributes effective outcomes to its own efforts and strengths. An empowerment and enablement focus leads to gradual strengthening of self-efficacy and self-esteem rather than to dependency and a sense that control of family problems can only be achieved through the help of experts. In this approach a working assumption is that all families have strengths and that all families can learn, grow, and develop in order to better meet their needs.

There is a need to translate these philosophical positions into concrete practices in the field of head injury. It appears that a lot of craft knowledge currently exists about how to provide assistance to families in an empowering way. However, these methods currently rely upon the individual skill of a few experienced practitioners and have yet to be translated into reliabie methods and procedures that can be widely replicated. Work on new alternatives to traditional case mangement is an important area for future research and model development in the field of head injury .

References:

Dunst, C. Trivette, C.M. and Deal, A. (1988) *Enabling and Empowering Families: Principles and guidelines for practice*. Cambridge, MA: Brookline Books.

Moroney, R.M. (1986) Shared Responsibility: Families and social policy. Chicago: Aldine.

A Summary of Conclusions from the Conference

Societal Principles:

1. Effective family support is built upon the principle of interdependence and can only be provided in a context of adequate societal support for all families. This support may involve specialized services, generic equipment, services and programs with specialty and adaptive components, and mechanisms such as guaranteed medical treatment, caregiver leave for family emergencies and crises, and other mechanisms which underpin a sense of community responsibility for all of its members, including those who are temporarily or permanently vulnerable.

2. Supports should recognize the great diversity in family structures, ethnic and cultural identities and regional and local subcultures featuring equal opportunities but not the same treatments.

Service Philosophy:

1. Families have strengths and have a desire to become allies with professionals in meeting the child's and family's needs when they are approached in positive ways.

2. Families can and should play a crucial role in the treatment, rehabilitation, and social integration of children and youth with traumatic brain injur

3. Trauma to a child is a traum to the whole family; the family must be actively supported in order to cope effectively and mainta nd enhance inherent strengths.

Service Systems:

1. Control of services that impact the family should be vested with families.

2. Services should be comprehensive and of high quality. For example, professionals should have appropriate and current information, should demonstrate the knowledge and skills appropriate to their tasks, have professional credibility and appropriate experience clinically/ programmatically as well as skill in working with families.

3. Services should be provided in locations and through means which build, strengthen, or activate informal sources of social support for all family members.

4. Services should be provided through the most valued and typical or "common to all" means which are compatible with personal growth and rehabilitation goals.

5. Services should aim to promote positive outcomes, prevent problems, and ameliorate problems that arise for families. That is, there should be a break with the tradition of providing help only to the most needy in order to rescue families from the most dire of outcomes.

6. Services should feature clear communication of information which also includes concrete ways in which a concern for the social and emotional needs of family members is met. This should be a measurable hallmark of all phases of treatment, rehabilitation, and community integration.

7. Services should have a goal of egalitarian alliances between professionals and families in which the strengths of both are valued and utilized. Planning, implementation, and documentation should be able to demonstrate in concrete ways how this is happening.

Possible Action Steps

The conference participants decided that they would lay out some strategies and actions which would be pursued by individuals in the group.

Action Steps

1. Prepare recommendations to CARF for the January 24, 1991 conference. These recommendations should be aimed a creating standards for family centered rehabilitation services.

2. Collect models of new alternatives to case management, the role of the integration facilitator, and disseminate the concept to allied organizations. Send out a questionnaire seeking models/contacts, interview contacts, and summarize. Especially look into SKIP (Sick Kids Need Involved People -- Kathy Swaninger or Margaret Mikol in NYS, Gillette, and a school/rehab model.)

   a. sponsor a conference that brings together disability groups to focus on recommendations about reforming case management
   b. prepare a report that gives examples of new models
   c. determine how different models might fit into existing service systems--for example, in New York State.

3. Collect models of how to empower families so they can obtain maximum benefit from IFSPs.

4. Contact JCAHO, request family standards, distribute and draft alternatives.

5. Pursue training and education recommendations.

   a. contact head injury centers to determine what materials exist

   b. create a brochure or videotape for families--Singer and Nixon will make a video and audiotape from their study

6. Recommendations from the November 9, 1990 meeting sponsored by NYSHIA should be circulated at the NHIF conference in June. Input should be obtained from parents and survivors. Recommendations should be presented to the organization to be adopted as goals.