

FAMILY DAY FORUM

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BRIDGING THE GAP: PROFESSIONALS AND FAMILY TOGETHER

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Objectives:

1. That both professionals and family members identify strategies for successful transition from hospital to home.
2. That some myths, held by both groups, may be explored and exposed.

This presentation will comment on difficulties that are experienced by brain injured people, their families and concerned professionals in the transition from hospital to community. These difficulties may be compounded by misunderstanding, poor communication as well as practical matters such as pressures on time.

My experiences, as a rehabilitation professional working in specialised units and currently as a community based Case Manager have enabled me to have some awareness of the issues involved and to have worked with both professionals, brain injured people and their families to achieve greater cohesion and often reduced friction.

Strategies discussed will include using a Case Manager to act as a coordinator and to communicate with both groups and the importance of shared goals, which are understood and prioritized by all. Thorough assessment of the demands likely to be placed upon the family and their ability to meet those demands is essential. Poor planning, lack of resources and unrealistic expectations all contribute to family conflicts and a breakdown in the relationship with the professionals.

It is vital that neither group feels that their own knowledge and experience is more or less valid than the other's, and no assumptions should be made about other's experiences.



THE NEED FOR HOSPITAL/COMMUNITY INTEGRATION IN ITALY

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The recovery from coma is a process that requires several interventions (rehabilitation, nursing, social services, educative and re-employment interventions).

The integration of interventions is the most important factor to obtain good outcomes (1), so it is a crucial issue in the organization of effective services for adult disabled people.

In the 1996, the Trauma Association of Parma (Italy) suggested to the social services of Parma an hospital/community integration project. The project proved to be problematic because of frequent changes in the social services organization at that time.

Fortunately in the following years new laws and documents, about social policy in adult disabled people, have emphasized the general absence of services, the big dis-homogeneity from north and south italian regions, the big burden that family of disabled people are bearing nearly always, and the need to build up an integration between hospital and community interventions (2, 3, 4, 5).

The italian political solution, with regard to services integration process, is to subdivide the territory into Districts, which have two principal aims: to assess the social and health population needs, and to commit hospital and social services to support that problems (6). Every District has got to develop a multidisciplinary staff to build knowledge about adult disability needs and territorial hospital/community services.

Now, the hospital/community integration process is possible, but it will be realized only if acute and post-acute Rehabilitation Centers will be ready to organize themselves into integrated networks with territorial social services and if Directors of Districts will manage the process with attention and firmness.

References:

- 1) *Semlyen J.K., et al. Traumatic Brain Injury: Efficacy of Multidisciplinary Rehabilitation. Arch Phys Med Rehabil 1998;79:678-83*
- 2) *Italian Law 5 february 1992, n° 104.*
- 3) *Italian Law 21 maj 1998, n° 162.*
- 4) *Handicap Policy, Government Action Program 2000-2003*
- 5) *National Conference about Handicap Policy*
- 6) *Decreto Legislativo 19 june 1999, n° 229.*



REACHING OUT TO THE COMMUNITY THROUGH THE MEDIA WITH A PUBLIC SERVICE CAMPAIGN

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Traumatic Brain Injury is the leading cause of death and disability globally, due to motor vehicle crashes, sports injuries, falls, and violence. In the United States alone, according to the Centers for Disease Control (CDC) “5.3 million Americans are living with long term, severe disability as a result of brain injury and as many as 6.5 million Americans are living with some form of permanent effects of mild and moderate brain injuries. The estimated cost in the United States is \$48 billion annually”. We as a community must band together to make our voices heard. We as a community need to reach out to the media so that the “Silent Epidemic” is no longer silent.

One of the methods of public awareness is through the media. Examples of such outreach will be demonstrated by the showing of public service announcement films developed for American and Canadian Television.



HORMONAL ISSUES IN BRAIN INJURY REHABILITATION

Christopher G. Zitnay, MD, Virginia, USA

During the acute phase following traumatic brain injury (TBI), there are several well-documented neuroendocrine hormonal imbalances that occur, which can be predictive of survival. However, during the post acute rehabilitation and community reintegration phases, hormonal dysfunction is a common but often-undiagnosed problem. Studies show that around 40% of individuals with a moderate to severe traumatic brain injury have a disturbance in at least one hormonal axis. The clinical signs of hormonal dysfunction can be mistake for depression or cerebral dysfunction as a result of the brain injury, and are often ignored. Secondary gonadal failure and growth hormone deficiency are the most common hormonal dysfunctions following TBI yet any of the pituitary hormonal systems can be affected.

As of yet there are no standardized evaluation pathways that have been established to screen patients for neuroendocrine dysfunction following TBI. Since the neurobehavioral symptoms of hormonal dysfunction that can mimic the symptoms of brain injury and since those symptoms caused by hormonal dysfunction are reversible with proper therapy, it is important for the clinician to be aware of the possible existence of neuroendocrine dysfunction and how to properly screen for it.

In this discussion the current literature will be reviewed and strategies concerning post TBI hormonal dysfunction for both families and physicians to follow will be examined.

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QUALITY OF LIFE AFTER BRAIN INJURY: ISSUES AND ADVOCACY

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1. Brain injury, unlike any other ailment, has lasting impacts upon the life of not only the survivor, but also the family, friends and the community they live in. Brain injury demands major changes in the lifestyle of the brain injured and their family. The problems are unique, innumerable and varies from each injury/individual. The treatment and diagnosis are equally difficult decisions from identification to treatment. These are augmented by the lack of awareness about brain injury and treatment. Its impact on the individuals and their families is incomprehensible. Even today, most people and even the Health Care Providers / and the medical community are not fully aware of its impact.
2. Thanks to Brain Injury Association (USA) and its affiliates, International Brain Injury Association, Canadian Brain Injury Association, Brain Injury Associations of United Kingdom, Italy, Spain, Denmark and other European Brain Injury Associations, Australian Brain Injury Association and others through out the world,who have been contributing a great deal of efforts in promoting brain injury from prevention to identification and treatment. Several research materials have been published on this subject and the collaborative efforts due to IBIA has been contributing to many more increased and joint efforts. These organizations are contributing to the importance of more research and remedial actions which are necessary to prevent, identify the depth of the impact of these injuries and the treatment aspects. While there has been major breakthroughs in research and understanding of the brain injury, as well as in educating the public, especially over the past decade,we still, have a long way to go.
3. The one area which still needs to get more attention, is the mild and mild-moderate brain injuries, especially with repeat injuries occurring within six months after the first injury or after a long time. Its effects on high performers to average performers, temporary recoveries versus, long term effects on their functional difficulties, psychological and social implications, overall performance, effects of medications and therapy, etc., needs proper attention. There are serious issues that needs to be addressed in order to overcome many of the obstacles the survivors, families, insurance industry, the Government and even the health care providers face. There is a tremendous need for understanding and obtaining support for the survivor/families. To accomplish understanding various aspects of the brain injury and its successful treatment, there is a great need for advocacy from people of all walks of life. In order to do this, one avenue is to educate the public. In today's session, I will try to bring out some of the important issues based on individual



experiences. I have come to know some of the important issues through self experience as well as meeting several survivors and their families/friends met personally or hearing their stories from the survivors, through support groups, telephone conversations etc. and seen many similar problems faced by all of the survivors and their families as well as some cases which are very special. There is widespread lack of empathy and understanding in the survivor's day to day life from one and all.

4. Individuals with brain injury who look normal to most people, especially with mild to moderate brain injuries suffer and have come to understand that they may have to put up with most of the residual cognitive, communication & psychological problems for the rest of their life. They have to cope with numerous short comings on a daily basis. The significant changes in the lives of brain injured is sometimes recognized only by the people very close to them because of the multitude number of problems. At times it does seem very lonely and difficult for them to continue even with their routine chores as they sense the differences between them and others. A supportive family, understanding friends and encouraging surroundings, in addition to good medical care and less bureaucracy will help processes that they have to go through to obtain the necessary help. If everyone concerned understood the issues better, people with brain injury and their families would find it easier to cope with their problems. For this purpose alone, advocacy is a must for all concerned including for people with brain injury, their families and well wishers in the community.
5. To stress the need for advocacy, I am going to give some of my personal experience as example. The quality of life changes in several respects, each individualistic, ranging from monetary stability to social integration and participation. When we hear that someone, unfortunately, is undergoing cardiac surgery or chemotherapy, almost everyone understands how difficult it is and are empathetic. We the brain Injury community should be able to create this kind of awareness and receive the same kind of treatments from general public to the Governments around the world.
6. For those of you who are familiar with brain injury, you very well know the difficulties. It is not only the injured who has to endure so much suffering, but family and friends equally, if not more, experience the hardships. Brain injury, unlike any other injury or illness is neither easily identified nor properly diagnosed and treated, especially, the mild to moderate brain injury. Sometimes, it has taken years, before it is even recognized as a brain injury. Some of the effects of brain injury may become noticeable after many months or even years after the injury.
7. Every brain injury is unique and the symptoms vary. Therefore, the most important thing after suffering a brain injury is to get a second, third or as many as needed opinions until it's properly diagnosed. Very often, brain injury patients also suffer



from psychological problems in addition to physical and other problems. Once it is diagnosed, it is most important to find the right doctors and therapists to help the brain injured and their family to cope with the situation. In addition to the neurologist, it's desirable to include a cognitive/communication expert, Neuropsychologist and a Psychiatrist with knowledge of brain injury to closely work with the Neuropsychologist, and in due course a Psychiatrist in the treating team of experts. It's equally important to get family counseling. I can't emphasize enough the importance of these aspects from the early stages. I say this so definitely and emphatically, based on several facts as I know.

8. The deficits caused by the multiple minor brain injuries result in cognitive deficits, that affect many activities, in terms of speed, efficiency, integration, attention etc. The problems are wide spread and ever changing. Psychological coping with these problems is a very hard task. This affects emotional stability greatly. Easy fatigue and headaches, depression and attention problems, etc. limit a lot of activities. At times, not being able to understand what is said by others, misunderstanding what is said, creates serious problems. Family and friends have to deal with repetitive and ruminating problems; forgetfulness; mood changes; and spontaneous outbursts of anger. Having to depend on health care professionals and family to organize even a simple task makes one's days very structured and guarded. In addition, performance during a task, if it ever gets completed, depends upon several factors: physical problems; effects of medication; sleep; stress & mood factors; other psychological problems; etc. At times, one may or may not be able to do even mundane and repetitious assignments. In other words, one or several days a person with brain injury may carry out a task reasonably well and the same or similar task may turn out just the opposite results at other times. There is no consistency in performance. Sustaining any activity even for a short period at times becomes a major stress factor.
9. Given the problems elicited above, life after brain injury is remarkably different from what it used to be before. People who can carry on a profession and stay on after brain injury are very fortunate and are very few compared to who cannot. However, the frustrations and short comings of those who cannot, need to be understood by all concerned people. Integration into the work force in addition to the social circle is a problem that needs help and understanding by everyone. In order to get back to a manageable level one cannot ignore the issues and conflicts in the legal and insurance aspects, in addition to the family integration. Advocacy and education of the communities will improve the quality of care and remove some of these major hurdles in treatment and recovery of the brain injured.



BUILDING BRIDGES

Rita Rees, MBE, Bristol, UK - Deputy Chairman
Headway National Brain Injury Association
President, Brain Injury European Confederation

Bridges have to be built from the beginning of the trauma associated with Brain Injury. The time in the acute hospital is difficult as families come to terms with the injury, managing family life and lack of knowledge of what is happening.

This building has to continue from the hospital situation to the difference experienced in the rehabilitation unit, to the outpatient situation and finally, if possible, to independent living of their injured loved one.

Life to the families is a continuous adaptation, making friends with whoever is concerned with the situation at that particular stage and wherever their family member is receiving help.

Whilst it may appear they are receiving help at all times, the families are giving too, even if it is surrendering their own likes and dislikes, what they think is best or worst, or just sitting on the sidelines.

Bridges have to be built from both sides, the professional and the family, if a reasonable outcome is to be achieved. It is difficult for the professional, dealing with the entity of the family, who stick together at all costs. They too may feel that they are continuously giving in to the strong unit of the family, but it is essential that both sides strive to build bridges. It is also essential that Governments recognise that the bridge is not complete and that provision is made for the brain injured to live complete and independent lives, at the same time providing the best care possible.



MEDICO-LEGAL ASSESSMENT AND COMPENSATION

Giovanni Cannavò, MD, Pisa, Italy

In the past, in order to assess personal damage following cranial trauma, greater attention was devoted to the physical and motor disabilities rather than the psychic deficiencies and social problems. Assessments objectively focused on demonstrating the type and extent of neurological troubles, as opposed to the greater difficulty in assessing the psychic ones. Thus, rehabilitation services currently tend to be structured almost exclusively on the type and extent of neurological troubles, while the patient and family members are often afflicted by psychological, social, and at times, clearly psychiatric ones.

The psychiatric, post-traumatic disorders are quite frequent and are nonetheless difficult to assess from a nosographic point of view, making this a remarkable problem when giving a legal medical assessment.

Although cranial trauma is clearly related to the onset of psychiatric disorders, there is contrasting data about slight cranial traumas causing secondary psychiatric disorders. Contrarily, there are few doubts regarding the psychopathogenic capacity of medium to severe traumas affecting the brain area.

Thus, in terms of correctly assessing and properly compensating damage, it is important to study the relationship between brain dysfunction and psychiatric illness, which, thanks to the use of greatly reliable, modern and sophisticated neuroimaging techniques and neuropsychological tests, is possible.

The proper definition and quantification of psycho-pathologic sequelae affecting the ideo-cognitive sphere and of behavioural modifications include complex problems of a practical nature. Provided it is possible to prove that the psychic disorder existed prior to the trauma, a worsening of the psychic conditions of the person is, however, nonetheless a type of personal damage which could arbitrarily be lessened by attributing it to the victim's peculiar vulnerability.

In fact, singling out the cause-effect relation seems to be particularly difficult, as the widespread scepticism leads to discovering only "occasional" links. In addition, subjective predisposition is however considered as an unavoidable factor due to the underlying and widespread common sense conviction, shared not only by jurists, that people are masters of their fate. This means that in negative situations, victims are considered latently responsible, because they did not behave in a certain manner or because they did not react nor overcome the traumatic events thus being uninjured. The recognition of the entire cause-effect relation of the psychological damage seems to be a critical issue regarding the change of attitude.

Faced with the casuistic and the seriousness of many situations, the conviction that a truthful cause and effect relation exists is becoming popular, although one often limits oneself to the contributory cause of the event within the practice.

From a legal and medical point of view, "psychological damage" is undoubtedly part



of the biological damage concept, which must necessarily include soma and psyche at the same time. In fact, personal damage is not only biological damage, but also injury of any inviolable right, including the right to health. Biological damage, although fundamental, does not thereby include health damage. Psychic damage is therefore currently recognized even if physical impairment is missing, which is something that was initially considered just as important in order to have a tangible data of reference.

The recognition of “mourning damage” as well as any reference to “psychological stress” is evidence of the way psychic damage may manifest. It should therefore also be compensated as a “strictly psychic damage”, aside from any physical substrate.

Medical examiners begin by defining the clinical extent of the injury to the victim’s brain and by trying to reconstruct his or her pre-trauma personality traits, which interfered as a concause of the disability, without eliminating the cause-effect relation. In fact, a diagnosis cannot be given by technological medical instruments, yet it is necessary to ponder upon the persistence of the psychic disorder and facing its incidence on the person.

The consequences facing the victim’s family should not be neglected to such an extent that severe brain trauma may not be considered only as pathology affecting the individual, but rather as a disease affecting the entire family. In particularly severe cases, some courts are in favour of compensating non-financial damages suffered by the relatives of the macro-injured person, such damages are often referred to as “damages to family peace” or “indirect damage”.

This allows for a new damage category, the so-called “reflected damage”, which is a peculiar form of biological damage of a psychic nature, whose monetary compensation adds to the consolidated damage categories ordinarily creditable to secondary victims.

This type of damage does not only apply to the death of relatives, but also to other “relational deprivations” such as the cessation of sex with the primary victim, due to peculiar psychic and physical disabilities caused by the trauma. This responds to the need to consider any damage to the relative’s psychic sphere, ensuing not only from the death of the primary victim but also from his or her disabilities jeopardizing the qualitative and quantitative level of its previous personal interactions within complex cohabitation and intimate relationships.

In fact, one cannot neglect that, if the primary victim’s slight disabilities hardly induce reflected, biological or even moral damages to relatives, then it is not unusual that severe impairments may jeopardize the family relationship, by causing moral and also biological damage.

In addition, the sexual function, facial and aesthetic modifications, which account for less than 50% of the fees, may cause serious reflected, moral and biological damages within family and marital relationships.

Thus, medical examiners should and could greatly contribute by appropriately defining new types of damage to be compensated, making it possible to differentiate as best as possible the transient, subjective sufferings from the clearly psychopathological, objectable and permanent disabilities. It is necessary for medical examiners to implement their specific contribution to the doctrine and to the expert field, by actively



looking for the contribution of other disciplines while giving a diagnosis and by paying proper attention to any connections and to the damage assessment method. It is thus necessary to carry out the following: an anamnestic-circumstantial inquiry, which pays particular attention to the type and intensity of the interpersonal relationship between the primary and secondary victim; a qualitative-quantitative assessment of the destabilizing effects of the primary victim's damage on the relationship; a well thought out analysis on the causal/concausal connections between the secondary victim's psychic/psychosomatic disorders, his or her previous personality traits and the primary victim's impairments; and a diagnostic judgement regarding the permanent nature of the disorders. Above all, it would be necessary to widely define accepted assessment principles allowing for a diagnostic assessment that can be verified, repeated and interpreted universally.

In fact, attorneys, insurance companies and judges should be given useful parameters on whose basis a fair compensation in line with current reality can be offered, since current reference tables on biological damage seem to be inadequate instruments in defining the permanent biological damage within the psychic one. In fact, one should not assess an isolated psychic disorder, but rather how much the specific disorder impairs and diminishes an individual's psychic and physical integrity, relational life and working ability.

In addition, while assessing the psychic damage, it is impossible to resort to rigid systems based on tables. It would be more correct to use a "range criteria", keeping in mind that offering less than a 10% psychological damage is meaningless. In fact, an individual's "normal" ways of being and changeable states of mind at different times and during different life experiences are actually part of the above-mentioned range.

The psychologists' and psychiatrists' difficulty in drawing up a table containing something that is not measurable in percentages adds to the complex quantification of the psychological damage. In fact, psychic integrity cannot be measured on the basis of a "normal state" which does not have much to do with psychic subjectivity. This is where the various disciplines greatly differ, since human sciences do not aim at quantifying psychic integrity. Yet, they shall learn to respond to such a question, in order to aspire at least to offer "a full protection of the human being".



SUPPORTING THE FAMILIES OF THE BRAIN INJURED

Manuela Cano, Medical director / L'ADAPT - La Vallée, Betton, France

- When and how long?

- * From the very beginning that's to say, starting from the neurosurgery or intensive care unit, by meeting them, explaining the "after-intensive care unit", the rehab team, the guidelines of rehab programs.
- * All the way long during the rehab period.
- * After the rehab period, all the way leading back into the community and even when this stage is performed as to maintain the situation and prevent every possible decrease by a social and rehab follow-up either by the very first team or, preferably by independant but well-trained carers. It's very important to create these links before the BI person lives the rehab unit , so that the family doesn't feel lost and abandoned.

- Who?

every member of the rehab team has something to do with this support: MD, social worker, neuropsychologist, psychologist, and every other member of the rehab team (nurses, physiotherapists, OT, speech therapists, leisure and sport educators,...)

- How?

Time, explanation and listening are the key-words!

- * We're trying to develop our receptiveness sharing time as much as necessary with the families, sometimes several meetings a week to begin with, that's to say, nearly as many times as they want or need it.
- * We give all available information about the medical case and repeat all the explanations as many times as needed; families received those informations at the intensive care unit but either, the words weren't simplified enough, or the suffering was too strong for the family to be receptive to any kind of explanation.
- * The neuropsychologist and the MD mostly, but also the entire team are giving all the necessary clues to be able to cope with the BI person and her new way of behaving, talking, understanding as well as about all the physical deficiencies.
- * While the rehab team is working, the social worker is a master-piece between the family and the community, the insurance companies and the health services, supporting and advising all through the required procedures.
- * We, as professionnals, must be very patient, waiting as long as necessary, for the family to be ready to accept the next stage of the recovery process. Though we roughly know the way the future is going to be for this or that BI person we should never tell a prognosis. First of all, we never know for sure and second, the family needs time to observe, experiment and change at her own speed, following her own way. She is the one who knows; we mustn't tell her what to do ; we're only there to



guide her and support her all through their experiences of this new life; as Louis Emery said “the institution is a tool box whose key is in the families hands”.

References:

- *Hand book for the families of head injured patients - MH Boucand, J. de Labarthe, E. Richier*
- *La compétence des familles - Guy Ausloos - Editions ERES*



GUARDIANSHIP: FROM THE HEAD TO THE HEART

Luisa Bosisio Fazzi, Parents Association "La Nostra Famiglia", Bosisio Parini (LC), Italy

At a recent World Conference, a person with an intellectual handicap was asked by some "normal people": "What should we call you?".

His answer was: "Call me mister".

That is what it's all about. To be treated with respect and dignity. To be listened to. To have equal protection by the law. To have duties in the community like everyone else. To have an adequate standard of living.

(Statement by Mr. Victor Wahlstrom, UN and Human Rights Co-ordinator of Inclusion International. UN Commission on Human Rights, 54th session - March/April 1998)

By law the legal capacity is acquired by all people, whereas the capacity to act is normally acquired at the legal age (majority).

What happens when legal age does not match full psychic and intellectual maturity due to a mental illness or a cognitive deficit?

The legislative system then tackles the issue with the institution of guardianship, based on the incapability model. Any incapability situation is responded to by the means of guardianship.

What is the general approach, within the institution of guardianship, to the problems of people with functional difficulties due to impairment (or people with disability)?

Formally it is the protection of individuals who are not sound of mind, but in reality it is a discipline which compromises, sometimes severely, the possibility for a person to choose freely, on the basis of her/his life, the need for protection from potential self inflicted harm, if she/he were acting independently; this discipline has revealed to be aimed at protecting patrimony only. It is not a Human Rights oriented approach, based on equal opportunity for disabled citizens and so aimed at the possibility of an "inclusion" in social life.

What does it mean to protect and defend the individual?

First of all, protect means "allow to live", ie. allow satisfaction of the most essential needs. Protect means intercepting what could harm the person and defending from it. It means adopting measures oriented towards integration and to fighting the risk of social exclusion. It is a project oriented approach, aiming at increasing the possibility to participate in social life. Secondly, protect means increasing the opportunity to live and participate in equal terms. It is accepting and implementing a perspective of Rights, whereby the subject is not the person in charge of protection, ie. the authority which believes to hold the technical tools to decide for the person with diminished capability, but indeed the latter her/himself.



The will of the protected person is central, even when there is lack of capacity to fully understand. Imposing the will of a third party must become, increasingly, a “last resort” strictly reserved to cases of most severe disability. In these severe cases, the will of the protected person should remain within the remit of the parents or close relatives. Not because they share interest in patrimony, but because they live close to the disabled person and are best aware of his/her real needs and interests.

The person with diminished capability needs help, support and protection. Because there are different levels of incapability, it is obvious that there are different needs, and hence the level of support provided must reflect the actual grade of incapability.

More help than is actually needed is by definition an unjustifiable limitation of personal freedom, which constitutes a violation of a guaranteed constitutional right, a violation of a Human Right of all, including disabled persons.



TALKING WITH PROFESSIONALS: A CONSUMER PERSPECTIVE

Barbara A. York, a 9 1/2 year survivor of a traumatic brain injury

From the first moments of learning a loved one has been involved in a serious accident, communication plays a key role for the family members, as well as for the person with a brain injury. Both are immediately thrust into world of new experiences within the medical community and interpreting the foreign language of medical terminology often presents many challenges. With the discussion of topics ranging from diagnosis to prognosis to rehabilitation to insurance, the health care provider, family, and person with a brain injury must communicate well together in order to create a trusting and successful relationship.

Barbara York, a 9 1/2 year survivor of a traumatic brain injury, will discuss her personal experiences and lessons gained from her communication with health care providers. Her presentation will highlight topics frequently noted by families and provide suggestions for family members on how to make their relationships with their providers more successful.



