

# A holistic brain injury rehabilitation program for school-age children

Joseph T. Marcantuono<sup>a,\*</sup> and George P. Prigatano<sup>b</sup>

<sup>a</sup>*Department of Psychiatry, Clinical Neuropsychology/Neurorehabilitation, Riverview Medical Center, Red Bank, NJ, USA*

<sup>b</sup>*Newsome Chair of Clinical Neuropsychology, Barrow Neurological Institute, St. Joseph's Hospital and Medical Center, Phoenix, AZ, USA*

**Abstract.** In the field of pediatric neurorehabilitation, there is a dearth of well-defined models of care for children with brain injuries and research to support them. Literature reviews of both adult and pediatric studies suggest that programs involving a comprehensive and holistic approach to care may be particularly effective in addressing the issues faced by individuals recovering from acquired brain injury. The primary purpose of this paper is to propose a model of holistic neurorehabilitation for children with an acquired brain injury, and to describe its theoretical bases. The paper describes such a program developed at Children's Specialized Hospital in New Jersey, USA, and presents a brief synopsis of the program's philosophy, components, goals, and therapeutic interventions. In addition, the paper discusses the type of data necessary to demonstrate the clinical utility and cost-effectiveness of such a program, and calls for future research to examine this.

Keywords: Pediatric, neurorehabilitation, cognitive, rehabilitation, brain injury, TBI, treatment model, comprehensive, holistic, day treatment, therapeutic milieu

## 1. Introduction

In the field of pediatric neurorehabilitation, there is a dearth of well-defined models of care for children with brain injuries and research to support them [26]. Laatsch et al. [13] reviewed the literature and found only 27 published studies testing the efficacy of certain approaches. Of these, only one class I study was found [5]. It supported the use of a comprehensive rehabilitation program for children with acquired brain injury. This study and others reviewed by Laatsch et al. [13], coupled with findings from the adult literature on the potential effectiveness of comprehensive holistic programs for adults with acquired brain injury [7], lead to a reasonable question of whether such a model could be a valuable contribution to the field of pediatric

neurorehabilitation. The primary purpose of this paper is to propose a model of holistic brain injury rehabilitation for children, developed by the first author. Secondly, it describes the type of "data" that is necessary to demonstrate the clinical utility and cost-effectiveness of such a program for children.

## 2. Historical influences on the development of a pediatric holistic brain injury rehabilitation program

Early efforts at holistic brain injury rehabilitation programs for adults with severe traumatic brain injury (TBI) were described by Ben-Yishay & Diller [2], and later by Prigatano et al. [20]. These programs emphasized the importance of clarifying the underlying cognitive deficits that a patient demonstrates and teaching patients how to compensate for those deficits in the context of interpersonal relationships [17]. The importance of a therapeutic milieu for achieving these goals

---

\*Address for correspondence: Dr. Joseph T. Marcantuono, Department of Rehabilitation, Riverview Medical Center, 1 Riverview Plaza, Red Bank, NJ 07701, USA. E-mail: jmindset508@gmail.com.

in post-acute patients was emphasized. In due course, the problem of impaired self-awareness was also identified as a major barrier to returning brain dysfunctional patients back into a socially-reintegrated environment [3]. The role of psychotherapeutic interventions in the context of this treatment approach was also emphasized [2].

These holistic programs were not intended for patients with severe neurobehavioral dyscontrol. Their behavior was often disruptive to the milieu process and they were best treated by other methods [25,27]. However, for patients with moderate to severe TBI, who had sufficient behavioral control to work within the context of a milieu program, early research efforts into the use of such a model produced encouraging results [4,19]. Later follow-up studies replicated earlier observations and expanded insights [12,21]. The importance of the therapeutic alliance with patients and their families was shown to relate to rehabilitation outcome [21] and the maintenance of achieving rehabilitation goals several months and years post discharge [12].

Given these findings, the question naturally arose whether such programs could be applied to school-age children who had suffered severe brain injury, but had a reasonable chance of returning to the school environment and adjusting to the permanent (although changing) effects of their brain injury. The first author attempted to develop such a program to meet the needs of children. This program has developed over time, but was initially established in May of 2003 at Children's Specialized Hospital in Fanwood, New Jersey, USA.

### **3. A pediatric holistic neurorehabilitation program: Philosophy, structure, goals, and treatments**

While the work of Ben-Yishay and Diller [2] and Prigatano et al. [20] was with young adults, many of the goals and methods of interventions seemed potentially applicable to school-age children. Could one identify cognitive problems that underlay the child's major difficulties in adjustment? If this was possible, could a milieu environment using "coaches" help the child function at a higher psychosocial level within the context of group activities and ultimately within the school environment? Could specific techniques such as the "hot seat" method be successfully applied to children? Do children with severe TBI have impaired self-awareness and if so, could this problem be addressed within the context of individual and group activities

delivered in a holistic milieu day-treatment program? Could the child benefit from talking about his or her emotions and how they impact the child's self-concept and self-esteem? Finally, does aggressive work with family members, or relevant "significant others", result in a better treatment outcome for the child, as has been shown with adults [21]? These questions guided the development of the pediatric version of a holistic brain injury rehabilitation program.

Others have attempted to address some of these questions as well. Fletcher-Janzen and Kade [9] had developed an extension of the adult holistic model of neurorehabilitation for children, but did so for a post-acute inpatient population. They merged neurodevelopmental and neuropsychological paradigms of rehabilitation, and used an interdisciplinary team within a framework of a psychotherapeutic milieu [20]. They maintained the six stages of rehabilitation developed by Ben-Yishay [3] as the guiding focus of their interventions. Staff therefore works with the child within the context of a developmental framework over: 1) engagement in the rehabilitation process, 2) awareness of deficits, 3) mastery of compensatory strategies, 4) control, 5) acceptance of personal deficits and the ability to incorporate necessary changes in their life while 6) forming a sense of identity for the child. This neurodevelopmental model also influenced the model developed by the first author, for use with brain-injured children in an outpatient setting.

The structure of the day-treatment program developed by the first author closely parallels what is done with adults. Children are seen 5-1/2 hours per day for 4 days per work week. Patients are seen within the context of a milieu, which in the present model, is delivered in a simulated classroom environment. Children are referred to as "students" rather than "patients," and are separated into one of two groups, based on the child's age (6-12 years, and 13-21 years) or, alternatively, by the constellation of the patient characteristics at that time (i.e., the nature and level of neurocognitive functioning and primary areas of neuropsychological impairment). There is a maximum of nine children per simulated classroom, with a staff-to-child ratio of 2:1 or 3:1, depending on the training activities for the group.

Unlike the adult model, children are not treated "in cycles". Most children are in need of these services immediately following their discharge from acute inpatient rehabilitation, when they have surpassed the need for intensive inpatient medical management, but are not yet prepared to return to school. Children are therefore

accepted into the outpatient pediatric program on an open-enrollment basis, and are not limited to a certain time frame in which they begin and end their treatment program. Rather, their length of stay is determined by ongoing functional evaluations and the assessment of the child's progress toward the achievement of goals needed to succeed in school. The clinical staff is referred to as "coaches," and is comprised of an interdisciplinary group of therapists who work in an interdisciplinary fashion to achieve transdisciplinary goals.

Long-term and short-term goals are identified for each child. Long-term goals focus on the needs of the child as they develop and are established based on the age of the child and the extent and nature of their brain dysfunction, but overall, the goals involve the attainment of the six stages of rehabilitation developed by Ben-Yishay [3]. Short-term goals focus on the amelioration and compensation of cognitive impairments as they are presently observed within the context of a rehabilitation program. Thus, short-term goals focus on helping the child in the here and now to understand the nature of their deficits, verbalize their understanding of them, and finally, to identify and apply appropriate compensations to deal with their impairments following brain injury.

A fundamental difference, however, exists in the application of holistic neurorehabilitation principles to adults versus children, namely, with respect to self-identity. Children are, of course, in the process of development. The young adult, however, has a clearer image of "who they are." For the adult patient, the major problem after brain injury is dealing with their altered sense of normality [17]. For children it is a different scenario. The child has an evolving sense of identity at the time of their brain injury. They need considerable guidance in developing a realistic view of who they are now and how the brain injury may affect them as they grow.

Other additions and adaptations have been made to the model, in consideration of the unique characteristics of developing children, as well. For example, insights from Montessori [14] and Vygotsky [24] are incorporated into this pediatric model of care. In it, there is a strong emphasis on developing language as a method of coping and learning. Incorporating Vygotsky's theories into therapeutic techniques, the staff develops "apprenticeships" with the children in order to teach strategies and guide the child through increasingly difficult tasks within an environment of error-free learning [15]. Also, techniques such as modeling, scaffolding, articulation (i.e., child explains to the therapist

in his/hers own words what he is doing and why he is doing it), reflection (i.e. child is asked to estimate how they will perform on a given task and then rate their actual performance according to their prediction or standard), and increased complexity and exploration (i.e. child is engaged by the therapist in an exercise to "raise the bar" and attempt new tasks on their own) are some of the many "tools" used by the therapists to assist the child in meeting the rehabilitation goals. The children's success in integrating these strategic learning experiences into a schema relies on their ability to experiment at their own pace without fear of failure (Montessori). The psychotherapeutic milieu of the holistic pediatric brain injury program provides the context, or environment, for this form of learning.

#### **4. Admission/eligibility criteria**

Children with a history of acquired brain injury between the ages of 6 and 21 years, and who demonstrate neuropsychological and/or functional impairments secondary to that injury are eligible for entry into this rehabilitation program, regardless of pre-existing learning disabilities. Children with pervasive developmental disorders, autistic spectrum disorders, and/or mental retardation are not admitted. Children must be functioning at Levels VI to VIII on the Ranchos Los Amigos Scale, physically capable of enduring a 5-1/2 hour program four days per week, demonstrate sufficient levels of motivation and cooperation, and the ability to attend to a structured task for at least 15 minutes, with cueing.

Due to the emphasis on verbally-mediated treatment modalities, children must be able to understand and follow simple one-step directions and to communicate their basic wants and needs. Independence in activities of daily living (e.g., toileting, clothing management, feeding, etc.) are required, unless a personal aide or parental support is available to provide the necessary assistance for children who require close supervision of their ADLs. Also, the child must demonstrate adequate behavioral control and not pose imminent danger to self or others. Family members must participate in family conferences, family support groups, attention to the child's medical needs, and be compliant with all financial and legal matters related to their child's rehabilitation.

## 5. Goals

The long-term goals for each child are relatively generic and follow the six stages of rehabilitation [3] as adapted by Fletcher-Janzen and Kade [9] and described above. As is true with adults, the emphasis is on engaging the child in the rehabilitation process and having them become appropriately aware of their strengths and limitations. They are then taught mastery and control skills in order for them to appropriately manage their neuropsychological deficits in interpersonal situations.

After participating in the rehabilitation program for one month, and at least quarterly thereafter, the child, the parents, and the staff meet together to identify the specific short-term goals that will be focused on for that child. Using the Ben-Yishaian model, the staff identifies “linchpin” problems for a given child and develops a plan of action to help the child approach these difficulties within the context of a therapeutic milieu. Saturated cueing is used, along with the earlier mentioned techniques, to improve the child’s awareness and understanding of their difficulties within the simulated classroom environment. Goals are written in a fashion to increase awareness and understanding of the problems for the child. In this context, “poster goals” are established for each child and placed on the classroom wall. They target “the problem,” “the solution to the problem,” and the “strategies” (i.e., steps) that would need to be followed in order to ameliorate the selected problem. The child’s goals are presented to the child in full view and with the participation of the therapeutic community via the “hot seat” exercise described by Ben-Yishay. During this exercise, the child works with a “coach” in an intensive dialogue (appropriate to the child’s cognitive abilities) to understand the nature of the targeted problem, its solutions, and the strategies necessary for amelioration. The child restates the information in his own words, indicates his level of endorsement of the goals, and solicits feedback from the staff and his peers regarding their view of the child’s level of openness to the plan. This exercise allows for the therapeutic community to endorse the child’s treatment plan and to establish a “pledge” of assistance to help the child achieve their desired goals, and is a direct adaptation of the model utilized by Ben-Yishay and Diller [2]. The presentation of goals in such an exercise, the signing of a child-friendly “contract” symbolically indicating his or her endorsement of them, and the posting of the goals on the walls of the simulated classroom to remain in full view of the child and his peers helps to increase the likelihood of rehabilitating

better awareness and understanding of the deficits, and to encourage vicarious reinforcement and social learning for all students in the program. This practice also facilitates the probability that the child’s peers will become “peer coaches,” using cueing in various settings to improve the child’s overall utilization of compensatory strategies.

## 6. Therapeutic activities

There is a wide variety of therapeutic activities that are involved in the program. Various small group exercises are conducted within the context of the 5-1/2-hour per day program, with the content and complexity of the group exercises adapted to the child’s age and level of cognitive ability. Following is a brief summary of the group activities:

### 6.1. Focus group

The Focus Group is the first group of the day, and involves a 20 minute “breakfast hall” activity, the purpose of which is to re-orient the student to the milieu structure and to provide a “natural” setting to practice orientation, initiation, and communication skills within a social context.

### 6.2. Orientation group

This group occurs daily after the Focus Group, and runs for 40 minutes. Its purpose is to provide a sense of purpose/motivation for the day’s activities, to facilitate awareness and acceptance of one’s challenges, and to develop a habit of daily goal setting and self-monitoring.

### 6.3. Group counseling/play therapy

One of the program’s psychologists provides play therapy for the younger children, and group counseling for the older children/adolescents. The purpose of this group is to promote an understanding of the effects of the neuropsychological changes that have occurred following the child’s brain injury, and to provide a forum for working through the emotional and behavioral consequences of the child’s brain injury in a group of peers with similar challenges.

#### 6.4. Attention group

Attention Group is conducted twice weekly from 30-60 minutes, with the purpose of rehabilitating sustained, selective, and divided attention in both highly structured and increasingly distracting environments.

#### 6.5. Executive functioning group

This group focuses on promoting the development of the executive functions and reasoning skills necessary for functional independence in the community. It also provides opportunities for the rehabilitation of self-awareness of the child's areas of cognitive strengths and weaknesses.

#### 6.6. Memory group

The Memory Group introduces and reinforces various memory strategies to aide in the acquisition and recall of both verbal and visual information. The remediation of memory impairment is addressed through the utilization of a component skills deficit analysis and the development of individualized strategies to address the correspondent deficits (e.g. attention, executive functions, information processing, etc.).

#### 6.7. Language group

This group is conducted by a speech therapist, and focuses on the cognitive-linguistic, meta-linguistic, and pragmatic communication skills for the development of functional language pertinent to academic, community, and social settings.

#### 6.8. Movement/sensory-motor group

This group is conducted by an occupational therapist, with the purpose of facilitating the integration of cognitive, gross motor, and fine motor skills, in order to improve motor planning and performance of multi-level physical activities.

#### 6.9. Socialization/community group

This group focuses on the promotion of a sense of affiliation, the development of appropriate social interaction skills. It also provides an opportunity to verbalize feelings and concerns with regard to adjustment to disability.

#### 6.10. Activities of Daily Living (ADL's) group

The ADL's group facilitates the patient's ability to safely incorporate living and leisure skills into their daily repertoire. Treatment consists of activities that focus on meal planning and preparation, horticultural skills, board games, out-trip planning and implementation, individual and group crafts projects, money management, health and nutrition competence, safety awareness and basic first aid, transportation issues, household management, and as appropriate, sex education.

#### 6.11. Music group

Music Group is conducted in a small group format, with the purpose of promoting development of basic cognitive, creative, and executive functioning skills, while utilizing instrumental music as a therapeutic medium. The music group focuses on initiation, control, modulation, motor planning, attention, concentration, memory, information processing, social interaction, cooperation, persistence, and self confidence.

#### 6.12. Study skills group

This group is conducted in a small group format, with the focus of increasing the probability for transfer of learning of compensatory strategies to a student's school assignments. The group also allows the child an opportunity to apply metacognitive strategies learned in the program on tasks that are ecologically valid

#### 6.13. Reading group

Reading Group is conducted for the younger children in the program, one day per week, with the goal of promoting the development of necessary reading skills and reinforcing the cognitive strategies learned in the program to facilitate efficiency in reading, decoding, and reading comprehension.

#### 6.14. Writing group

This group is conducted in a small group format one day per week, with exercises involving expressive writing, pragmatics, motor planning, syntax, semantics, and verbal reasoning.

### 6.15. *Self-advocacy group*

This group helps the child to apply strategies acquired in the program to the function of self-advocacy. The group format involves discussions, role-playing, letter writing, exercises, and public speaking. Group activities are designed to focus on: awareness of deficits, problem solving, decision making, assertiveness, re-injury prevention, addressing environmental barriers, identification of environmental supports and accommodations necessary for re-integration into the community and school settings, and developing a responsible sense of self efficacy.

### 6.16. *Social applications I & II*

These are two separate groups which occur daily for 30 minutes each, and provide the children the opportunity to apply their cognitive and behavioral strategies in an informal snack and lunchroom setting. They also allow the staff the opportunity to assess the child's deportment and ability to transfer skills.

## 7. **Preparation for school re-entry**

Within the context of this program, children are provided individual educational tutoring by special education teachers who are familiar with the child's brain injury, the rehabilitation program model, and the child's underlying cognitive disturbances and strategies being taught. The tutors are contracted by the child's school district through the local county's Department of Special Education, but work within the context of the pediatric neurorehabilitation program. The child's rehabilitation goals are applied to the academic curriculum. This practice allows for the mastery, and habituation of skills in academic activities, and thereby facilitates the transfer of learning into the educational tasks and the child's role of "student".

## 8. **Family involvement**

Family stress has a profound impact on rehabilitation outcome for children [10]. Ponsford et al. [16] found that providing families with booklets that educated them on the typical sequelae of pediatric brain injury significantly reduced parental and child stress and misattributions for their child's neurobehavioral symptoms. Families need to be educated and empowered to

coach and advocate for their children within the community. Braga et al. [5] found that families can be intensively trained and supervised by therapists to provide effective rehabilitative interventions at home. Within adult models of holistic neurorehabilitation [8], the family's participation in the program has been found to promote greater levels of understanding for the rationale and goals of the clinical interventions, thereby increasing the family's willingness and motivation to carry over the interventions at home. This is also the case in the pediatric program described in this paper. For children, utilization of parents to reinforce skills at home is a "natural fit," as parents often oversee their child's development of skills and abilities in activities like homework, lessons, and practices in other venues of their lives. Thus, neurorehabilitation can be fit into a similar framework for many families, with the natural and reinforcing relationship between parent and child facilitating the child's mastery and habituation of strategies learned.

In the program described here, family involvement is strongly encouraged. However, many families' economic realities necessitate both parents working, and thereby limit their availability for direct and intensive involvement in the treatment program. Given these circumstances, the program endeavors to integrate families in the treatment plan via the following avenues. On the first day of their child's admission to the program, families begin the education process when they are assigned a "primary therapist" who acts as their child's ombudsman throughout the child's rehabilitation, and keeps the family up to date on the child's performance through regular in-person meetings or telephone consultations. The primary therapist, along with the program social worker, also acts as an advocate for the family as they negotiate the various inroads that need to be made throughout the long community re-entry phase, and often accompanies parents to related meetings in the community. Family members are invited to participate in weekly family support groups that are didactic and emotionally supportive. Each child is also assigned a psychologist who treats the child in individual and family psychotherapy sessions. In this way, the family is involved in ongoing education and communication regarding their child's performance, and is provided emotional support and guidance by the clinical staff in strategies their child should be practicing at home. This allows for the child to be supported in a system that understands and facilitates the child's application of the strategies learned in the program, without requiring the family to be the primary deliverer of services, nor to

attend the program daily. The family is also considered part of the discharge planning and community transition team while their child is in treatment, and they are encouraged to continue their participation in the family support group following their child's discharge from the outpatient program. They are also encouraged to join the local Brain Injury Association support groups.

## 9. Discharge and discharge planning

Since children are in a stage of development, it is often difficult to identify a clear point at which the child should be discharged from such a rehabilitation program. However, the rehabilitation team meets quarterly to evaluate the progress a child has made in numerous domains, and to determine whether or not they have reached a plateau where further rehabilitation efforts would seem either unnecessary or ineffective. This is a highly individual process, and is based on staff's ratings of the child's performance evaluated via a comprehensive rating scale of specific domains of functioning (e.g. control, attention, information processing, deportment) considered in the model to be markers of the child's progress and readiness for discharge from the program.

A transition team begins what is described as the "bridges program" at the time of the child's admission into the program. As the name implies, the goal of this team is to make appropriate connections between the rehabilitation program and whatever setting/environment into which the child will next be functioning. A social worker is utilized to help transition the child from the present rehabilitation program into any other further treating or care environment (such as the school or other rehabilitation settings). Consultation and collaboration is provided, with the intent of having the new environment tailored for the child's needs (as much as possible), and for the people working with the child to have a good understanding of the child's neuropsychological difficulties and how best to address them within the given setting. Typically, the child is followed for up to 5 years post injury, and participates in a "step-down" version of maintenance and ongoing individual rehabilitation therapies which gradually taper off.

## 10. The challenge of measuring the efficacy and cost-effectiveness of a pediatric holistic neuropsychological rehabilitation program

The efficacy of holistic brain injury rehabilitation programs for adults has been primarily measured by

the number of patients who could return to a productive lifestyle after such interventions [19,21]. It has also emphasized the importance of demonstrating the reduction of psychiatric comorbidity or complications that can frequently be seen in this patient group [20]. Measuring the efficacy of holistic brain injury programs for school-age children has only recently been discussed. Prigatano and Naar-King [22] suggest that four outcome measures should be evaluated when measuring efficacy for such work. Can clinicians/researchers demonstrate that children who receive holistic brain injury rehabilitation programs show 1) clinically-significant improvements in their capacity to obtain and maintain friendships and 2) their ability to improve academic performance and become more actively involved in academic pursuits? 3) Do their parents report reduced distress levels in the care of their children months and even years post rehabilitation? Likewise, 4) are the teachers' sense of distress in educating the child who has undergone such a program substantially reduced? While there are many other outcome variables that could be considered, these four areas appear to be crucial for demonstrating the value of a pediatric neurorehabilitation program that is holistic in scope.

To date, no such data has been collected allowing the quantitative analysis of these questions. The clinicians conducting this work, however, have the clinical impression that these changes do in fact occur for children and their families and teachers, having received anecdotal reports from patients, families, and school personnel of each of the above outcomes. In addition, parent satisfaction questionnaires administered at various points during the child's treatment and following discharge seem to support item number 3 above, as well.

Quantitative data presently available from this program consist primarily of neuropsychological test findings before and after rehabilitation. Improvement in Verbal and Performance IQ scores are generally noted, but this is commonly seen in children after TBI, irrespective of whether they receive rehabilitation or not [11]. Many children also show improved functioning in working memory, verbal and nonverbal memory, reasoning capacity, arithmetic skills, and social judgment. The challenge is to demonstrate, however, that these changes occur as a function of rehabilitation and that they maintain several months and years post injury.

Recent research with premature infants who undergo an intensive individualized rehabilitation program aimed at reducing their distress and improving motoric, cognitive, and affective functioning has shown impres-

sive results concerning the child's developmental state and actual changes in brain structure as a result of such interventions [1]. Those involved in holistic brain injury rehabilitation programs for children might well model this type of research in order to demonstrate the scientific value of their clinical interventions. Alternatively, development and utilization of long-term quality of life measures for children and their caregivers, specific to the needs and challenges of this population could also help to make valuable contributions to the further study of the efficacy of holistic programs in achieving their intended outcomes.

In today's healthcare economy, it is also important to demonstrate the cost effectiveness of any rehabilitation program [23]. There are many ways of measuring the cost outcome for rehabilitation. In traditional cost-effective research paradigms, one compares one form of intervention versus another in terms of the cost of the services and the observable changes that are a result of these two interventions. A natural starting point for demonstrating the cost-effectiveness for pediatric holistic neurorehabilitation programs is to measure the cost of this form of treatment versus individual outpatient therapies that are done in a traditional outpatient rehabilitation department (i.e., the cost of speech and language therapy, physical therapy, occupational therapy, etc.). One should also measure what types of gains are obtained for children receiving this form of treatment versus those obtained with other therapies. Indirect variables such as differences in the cost of medications, the cost of outpatient hospital visits, and the cost of school personnel that are needed to manage and educate the child, given two opposing approaches, should also be carefully considered.

Cost-effectiveness research also considers non-economic variables in making decisions about whether or not the service is of good "value" [23]. In addition to helping to answer questions regarding the efficacy of the program in achieving its intended outcomes, quality of life measures of the child and the family should be considered in analyzing cost effectiveness of such approaches. A rich area of potential research is measurement of quality of life of family members and teachers who care for the children who have brain injuries, and comparison of such findings between those who have undergone holistic pediatric neurorehabilitation, and those who have received another form of treatment.

## **11. Issues of insurance coverage**

A sad fact of life is that there are very limited financial resources to pay for brain injury rehabilitation

services. It is not uncommon that parents of these children are relatively young with multiple demands on their economic resources. Health care insurance policies have limits as to the extent of benefits and many do not cover indirect costs involved in placing a child in a day-treatment program. A further complication is that most school districts consider traumatic brain injury to be a "medical condition," and thereby do not consider it their responsibility to fund rehabilitation therapies, even though the condition does impact a child's academic abilities and performance. School districts, when willing to help, are also faced with the fact that they have limited budgets and have fewer resources to meet the special needs of children.

Many of the children who are referred to the holistic neurorehabilitation outpatient program have exhausted their benefits before they are admitted, or are faced with limited benefits for outpatient services. The Commission on the Accreditation of Rehabilitation Facilities [6] emphasizes the need to be sensitive to the fact that brain injury is a lifetime condition, for which conservation of funding in subsidizing treatment is essential. As such, individualized and carefully planned strategies for helping families to obtain the resources that are available through various venues, is essential in the delivery of a holistic pediatric neurorehabilitation program. Working with case managers of insurance companies, physicians to provide letters of medical necessity, school districts to provide transport for at least the tutoring provided on site, and representatives of other state- or foundation-based funding entities is essential to coordinate benefits for the provision of such services. A case manager, who is familiar with such funding agencies, and who is well versed in brain injury sequelae and the dialogue necessary to educate the insurers about the services provided is also an essential component for the practical delivery of such services.

Despite the challenges of limited resources, the program described in this paper has been able to remain financially solvent. This is largely due to good case management, and ongoing advocacy provided by the program to relevant agencies involved in the patients' and families' care and financial support of such. Undeniably, the ability to procure funding would be greatly enhanced by the ability to provide insurers and potential funding agencies with outcome data of the sort described in this paper.

## **12. Summary and conclusions**

The application of a holistic brain injury rehabilitation program for children is outlined in the present

paper, as well as the underlying theories and models which contribute to this method of care. The therapies that constitute the program have been outlined within the structured approach of Ben-Yishay and Diller [2], and adaptations made by the primary author are described. There are no outcome studies currently available demonstrating the efficacy of this work, nor data allowing for an analysis of its cost effectiveness. This paper was prepared, however, in an effort to describe the basic structure of the program, with the intention of disseminating the model to the field for further study and exploration by the professional community. Future research on the model and collection of quantifiable data will be essential in further exploring the efficacy and cost effectiveness of such a program in addressing the still sorely underserved needs of a population of pediatric brain injury survivors.

## References

- [1] H. Als, F.H. Duffy, G.B. McAnulty, M.J. Rivkin, S. Vajapeyam, R.V. Mulkern, S.K. Warfield, P.S. Huppi, S.C. Butler, N. Conneman, C. Fischer and E.C. Eichenwald, Early experience alters brain function and structure, *Pediatrics* **113**(4) (2004), 846–857.
- [2] Y. Ben-Yishay and L. Diller, Cognitive remediation, in: *Rehabilitation of the Head Injured Adult*, M. Rosenthal, R.R. Griffith, M.R. Bond and J.D. Miller, eds, FW Davis, Philadelphia, PA, 1983, pp. 367–380.
- [3] Y. Ben-Yishay and G.P. Prigatano, Cognitive remediation, in: *Rehabilitation of the Adult and Child with Traumatic Brain Injury*, E. Griffith, M. Rosenthal, M.R. Bond and J.D. Miller, eds, FW Davis, Philadelphia, PA, 1990, pp. 393–409.
- [4] Y. Ben-Yishay, J. Rattok, P. Lakin, E.B. Piasetsky, B. Ross, S. Silver, E. Zide and O. Ezrachi, Neuropsychological rehabilitation: Quest for a holistic approach, *Seminars in Neurology* **5**(3) (1985), 252–259.
- [5] L.W. Braga, A.C. DaPaz and M. Ylvisaker, Direct clinician-delivered versus indirect family-supported rehabilitation of children with traumatic brain injury: a randomized controlled trial, *Brain Injury* **19**(10) (2005), 819–831.
- [6] Commission on the Accreditation of Rehabilitation Facilities, *Medical Rehabilitation Standards Manual*, Tucson, AZ, 2007.
- [7] K.D. Cicerone, C. Dahlberg, K. Kalmar, D. Langenbahn, J.F. Malec, T.F. Bergquist, T. Felicetti, J.T. Giacino, J.P. Harley, D.E. Harrington, J. Herzog, S. Kneipp, L. Laatsch and P.A. Morse, Evidence based cognitive rehabilitation: Recommendations for clinical practice, *Archives of Physical Medicine and Rehabilitation* **81** (2000), 1596–1615.
- [8] E. Daniels-Zide and Y. Ben-Yishay, Therapeutic milieu day program, in: *International Handbook of Neuropsychological Rehabilitation*, A.L. Christiansen and B.Uzell, eds, Kluwer-Plenum, New York, NY, 2000, pp. 183–193.
- [9] E. Fletcher-Janzen and H.D. Kade, Pediatric brain injury rehabilitation in a neurodevelopmental milieu, in: *Handbook of Clinical Child Neuropsychology*, (2nd ed.), C.R. Reynolds and E. Fletcher-Janzen, eds, Plenum Press, New York, NY, 1997, pp. 452–481.
- [10] F. Florian, S. Katz and V. Lahav, Impact of traumatic brain injury on family dynamics and functioning, *Brain Injury* **3** (1989), 219–234.
- [11] K.M. Jaffe, N.D. Polissar, G.C. Fay and S. Liao, Recovery trends over three years following pediatric traumatic brain injury, *Archives of Physical Medicine and Rehabilitation* **76** (1995), 17–26.
- [12] P.S. Klonoff, D.G. Lamb and S.W. Henderson, Milieu-based neuro-rehabilitation in patients with traumatic brain injury: Outcome at up to 11 years post-discharge, *Archives of Physical Medicine and Rehabilitation* **81**(11) (2001), 1535–1537.
- [13] L. Laatsch, D. Harrington, G. Hotz, J. Marcantuono, M.P. Mozzoni, V. Walsh and K.P. Hersey, An evidence-based review of cognitive and behavioral rehabilitation treatment studies in children with acquired brain injury, *Journal of Head Trauma Rehabilitation* **22** (4) (2007), 248–256.
- [14] A.S. Lillard, *Montessori: the Science Behind the Genius*, Oxford University Press, New York, NY, 2007.
- [15] T.M. McDevit and J.E. Ormrod, *Child Development*, 2nd ed., Pearson Educational Inc, Merrill Prentice Hall, Upper Saddle River, NJ, 2004.
- [16] J. Ponsford, C. Willmott, A. Rothwell, P. Cameron, G. Ayton, R. Nelms, C. Curran and K. Ng, Impact of early intervention on outcome after mild traumatic brain injury in children, *Pediatrics* **108** (6) (2001), 1297–1303.
- [17] G.P. Prigatano, *Principles of Neuropsychological Rehabilitation*, Oxford University Press, New York, NY, 1999, Japanese translation, 2002; German translation, 2004, Berlin: Springer Publishing Company.
- [18] G.P. Prigatano and Y. Ben-Yishay, Psychotherapy and psychotherapeutic interventions in brain injury rehabilitation, in: *Rehabilitation of the Adult and Child with Traumatic Brain Injury*, (3rd ed.), M. Rosenthal, E.R. Griffith, J.S. Kreutzer and B. Pentland, eds, F.A. Davis Company, Philadelphia, PA, 1999, pp. 271–283.
- [19] G.P. Prigatano, D.J. Fordyce, H.K. Zeiner, J.R. Roueche, M. Pepping and B. Wood, Neuropsychological rehabilitation after closed head injury in young adults, *Journal of Neurology, Neurosurgery and Psychiatry* **47** (1984), 505–513.
- [20] G.P. Prigatano, D.J. Fordyce, H.K. Zeiner, J.R. Roueche, M. Pepping and B.C. Wood, *Neuropsychological Rehabilitation After Brain Injury*, Johns Hopkins University Press, Baltimore, MD, 1986.
- [21] G.P. Prigatano, P.S. Klonoff, K.P. O'Brien, I. Altman, K. Amin, D.A. Chiapello, J. Shepherd, M. Cunningham and M. Mora, Productivity after neuropsychologically oriented, milieu rehabilitation, *The Journal of Head Trauma Rehabilitation* **9**(1) (1994), 91–102.
- [22] G.P. Prigatano and S. Naar-King, Neuropsychological rehabilitation of school-age children: An integrated team approach to individualized interventions, in: *Pediatric Neuropsychological Intervention: A Critical Review of Science and Practice*, J. Donders and S. Hunter, eds, Cambridge University Press, 2007, pp. 465–473.
- [23] G.P. Prigatano and N. Pliskin, *Clinical Neuropsychology and Cost Outcome Research: A Beginning*, Psychology Press (First book in NAN Book Series), New York, NY, 2003.
- [24] J.V. Wertsch, *Vygotsky and the Social Formation of Mind*, Harvard University Press, Cambridge, MA, 1985.
- [25] R.L. Wood, *Brain Injury Rehabilitation: A Neurobehavioral Approach*, Croom-Helm, London, 1987.
- [26] M. Ylvisaker, P.D. Adelson, L.W. Braga, S.M. Burnett, A. Glang, T. Feeney, W. Moore, P. Rumney and B. Todis, Rehabilitation and ongoing support after pediatric TBI: Twen-

- ty years of progress, *Journal of Head Trauma Rehabilitation* **20**(1) (2005), 95–109.
- [27] M. Ylvisaker, L. Turkstra, C. Coehlo, K. Yorkston, M. Kennedy, M.M. Sohlberg and J. Avery, Behavioural interventions for children and adults with behaviour disorders after TBI: A systematic review of the evidence, *Brain Injury* **21**(8) (2007), 769–805.