The Child with Traumatic Brain Injury or Cerebral Palsy
The Child with Traumatic Brain Injury or Cerebral Palsy
A Context-sensitive, Family-based Approach to Development

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Foreword

Recent decades have witnessed an unprecedented increase in knowledge about the brain and its development. Advances in brain imaging have made it possible to identify, with great accuracy, the location of cortical lesions, and in many cases the brain structures that implement a variety of essential cognitive, motor, and emotional functions. Neurosurgery, benefiting from a wide range of technological innovations, has made it possible to remove diseased brain tissue in a minimally invasive way or to minimize the damage of traumatic injury to a particular part of the brain that threatens to result in secondary damage of nearby structures. Remarkable achievements in computer science have not only extended the range of diagnostic and surgical procedures, but have made possible the construction of prosthetic devices that were literally unimaginable in the middle of the twentieth century.

But despite all of these impressive gains in knowledge and the ability to support children who have suffered from brain injuries arising either from external causes such as a blow to the head or infarction resulting from congenital factors or events accompanying otherwise normal birth, many children and youths never fully recover from such brain injuries. A distressingly large percentage do not recover fundamental behavioral capacities sufficient to allow them to live with their families as members of their community. Not only does the inability of such children to acquire skills necessary to find a niche in society devastate their lives, it forces them to live in hospital facilities adequate to keep them alive, but not to afford them any semblance of normal adulthood. Such failures to find means to incorporate brain-injured children are ruinous for their parents and family members, whose lives are forever affected, whether by the burden of submitting their kin to the semi-human conditions of inadequate caretaking facilities, or of subordinating themselves to the often crushing burdens of home care.

Obviously, it is in the interests of everyone concerned that the possibilities of rehabilitation following traumatic brain injury, from whatever cause, at whatever age, be optimized. Yet, for reasons that are, ironically, linked in some measure to the scientific progress that has taken place in the diagnosis
and surgical treatment of brain injury – the high levels of specialization that are characteristic of the medical sciences – it is rare to find systems of rehabilitative treatment that optimize the potential for recovery, not only by providing optimal regimes of rehabilitative therapy within the medical and behavioral science professions, but by forging links with the families who will have primary responsibility for the integration of the child into the community once he or she is released from the hospital. After all, surgeons specialize in surgery and pediatricians focus on children with more or less acute, treatable diseases. Rehabilitation specialists may synthesize knowledge from many different areas of sensory, motor, and cognitive development, but by and large they are expected to work with recovering children in settings specially organized for that purpose. Given the need to see many children in the course of a normal work day, they naturally cannot be expected to be making house calls as it is far more efficient for children to come to them. Consequently, for perfectly understandable reasons, while injured children receive the best care that society can routinely provide, they do not receive the best care possible, except in cases where the parents are both exceedingly wealthy, well educated, and willing to devote their own time to the optimal rehabilitation and integration of their child back into their families and society.

Yet, without giving in to the illusion that all children can more-or-less fully recover from severe brain injury, we know, from cases where well informed and pervasive care has been provided for children who, under normal circumstances, could be expected to suffer devastating long-term effects of brain injury, that the potential plasticity of the brain, provided the right circumstances, is far greater than common sense, even well educated common sense, would suggest. This is especially true of young children, but there is ample evidence to indicate that functional reorganization of brain-behavior functions can be achieved well after the period when the brain is assumed to be optimally plastic.

From the classic work of Alexander Luria, we came to appreciate that even an adult for whom no modern computer prosthetics was available, a deep understanding of the functional organization of cortical functions can, in some circumstances, mitigate the effects of traumatic brain injury sufficiently for the patient, who in this case was an active accomplice in his own therapeutic regime, to return to life in his rural village and to enjoy some of the simple pleasures that life affords.¹ A sufficiently strong neuropsychological theory is an essential element in any program of rehabilitation.

We also know from recent research such as Antonio Battro’s study of Nico, a boy who underwent a right hemispherectomy at the age of 5, that well informed neuropsychological theory implemented with the full cooperation of parents who did not need to spare costs, and the potentials afforded by computer technologies that enabled high levels of dense and relevant environment stimulation can result in remarkable recovery of function.²
But these are individual cases. They are exceptional. What, in principle, does it require to create regimes of rehabilitation that make heretofore unthinkable levels of recovery possible? What does it require that parents without great economic means, and children who will never recover normal motor functions, can still be able to learn to communicate and live within a regime of care that is supportable by their families without superhuman sacrifices?

It is to answer these questions that this book is dedicated. The approach to the medical care and rehabilitation of brain-injured children described in the following pages takes its inspiration from an approach to integrating state of the art medical care in a specialized hospital, with an ongoing regime of parental education and involvement that integrates the work of hospital staff with the caregiving practices of the children’s families as a long term partnership.

For almost 30 years, a remarkable team of surgeons, doctors, psychologists, and rehabilitative therapists from the SARAH Network of Rehabilitation Hospitals have taken it as their basic task to work with parents and family members to make it possible for brain-injured children to return to their homes where they can live among family and friends as part of their local communities. By adopting the ability of such children to live in their homes and communities as the criterion for successful medical intervention, the SARAH team has created optimal conditions for children’s recovery. Rehabilitative therapy is no longer restricted to the hospital grounds where it must be carefully coordinated with the schedules of busy hospital personnel. Such experiences are of course essential, but they are not sufficient. To approach sufficiency, it is necessary to take as an ideal the goal that every moment of the child’s waking day will be organized to optimize the child’s development.

Since children are living with their families, the only way to create a maximally therapeutic environment is to make the family members a part of the rehabilitation team. This goal at first glance seems utopian. Even in industrially advanced societies such as those found in Europe, North America, and parts of Asia, it seems outrageously implausible to think that it would be possible to provide parents with the knowledge, motivation, and ongoing support that a fully implemented professional therapist-family circle therapeutic environment would require. But the SARAH group has shown that this goal is, in fact, realizable. Even families whose members are not well educated and who have modest fiscal means can be, and in the SARAH regime of care, are, integrated into a wholistic system of care for children that optimizes their life experiences.

Such an undertaking requires a great deal: strong theory (not only of the brain and its relationship to development and behavior, but of the sociology of professional work and its relationship to the lives of everyday working people); strong desire (none of the work is easy for any of the participants, it
spills outside of normal work hours on the one hand and on the other it stretches the boundaries of family life beyond normal bounds); strong support, not only from hospital administrators and family members but from society as a whole, as represented by their legislators and government officials. But, as the reader will discover in the pages to follow, such an undertaking is possible. It is even possible to develop it into the norm of medical care and rehabilitation for thousands of children in a country where many struggle in poverty and resources are, relative to wealthy neighbors to the north, scarce and often fragile.

This is a book worth reading not only for its practical lessons, but for its deep lesson about the possibilities of institutionalizing an effective, human form of medical treatment that should provide a standard for the world. Who dares to say they are doing enough, when they are not meeting up to the standard of science and care that is the daily experiences of the SARAH Network and its community?

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Foreword

It is a pleasure to write a Foreword to this wonderful book that Lúcia Willadino Braga and Aloysio Campos da Paz, Jr have put together. With their team at the SARAH Network, they have developed their own methods and style of rehabilitation for children with brain injury over many years. The principles and practice have been slowly refined and developed and this book is the culmination of their work. Their methodology of rehabilitation has been tried and tested on more than 15,000 children – both with cerebral palsy and traumatic brain injury. Although the results of their approach have been published in many articles and book chapters in the last few years, this book provides an invaluable summary.

Although each chapter is self-contained, the book is best approached by reading it in its entirety, as only then does the whole ethos of the SARAH rehabilitation approach become clear. In my view, the two essential components of the SARAH methodology are the major emphasis on multidisciplinary teamwork, and the key emphasis on the involvement of the parents and family in the whole rehabilitation process. The SARAH team have clearly demonstrated the benefits of family-supported treatment over and above treatment exclusively by professionals. It is very clear from their work that better outcomes can be obtained for disabled children by the direct involvement of the families in the rehabilitation process.

This book will be of great interest to a wide range of health professionals working in the field. However, it is also an invaluable source of reference for families with disabled children. It is written in an easy and comprehensive style and is free of the jargon that usually makes clinical textbooks relatively inaccessible to the lay reader. The book itself mirrors the philosophy of the SARAH Network in that it is a textbook for the whole team – the child, the family and the professionals.

If the reader wishes to take the subject further then each chapter also has a good range of key references. Each chapter is well illustrated with clear and helpful drawings of the difficult therapeutic approaches, which breaks up the text to make the whole book a pleasure to read. All aspects of child development are covered. Motor developments, unlike in may textbooks, do not take precedent over the equally important cognitive and neuropsychological developments in the child. It is the development of the whole child which is so important.
Foreword

One of the keys to the success of the SARAH approach is not only the involvement of the family but also the provision of accurate and meaningful information to the family in order to prevent misunderstanding and misinformation. This book is sensible, practical and provides clear, unambiguous information not only to clinicians, but also to the families of children with cerebral palsy and traumatic brain injury. I hope and believe this book will go some way to improving our knowledge, and thus provide a brighter future for children with disabilities.

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Lúcia Willadino Braga, PhD
Alysio Campos da Paz Jr, MD

Note on the text

Please note that for consistency, throughout the book, all children will be referred to as ‘he’ or ‘his’.
Children begin life with a view of the world that is filtered through the prism of their families. Their development is mediated, stimulated and strengthened through interaction with those closest to them. It is, indeed, the natural role of every family to stimulate the development of their child; they teach the child to explore objects, eat independently, to talk, walk unassisted and socially interact.

Once the diagnosis of brain injury has been established, both in cerebral palsy (CP) and traumatic brain injury (TBI), the mediation of the subsequent development or rehabilitation process is, in large measure, transferred to health care professionals.

The child is a whole person and the treatment depends on the participation of diverse professionals. Nevertheless, this group of sometimes wide-ranging specialists does not always work in a unified manner within a multidisciplinary perspective that understands the child as both a unique individual and a member of a family that has a profound interest in his development.

This book presents an approach that integrates the multidisciplinary team and the family, so that they can closely work together at finding ways to facilitate the learning and specific developmental processes of each child and adolescent based on their motivations, capacities and interests, within the familial and socio-cultural context.

At the core of this methodology is a program that is continually updated to accommodate the stages of the child’s development and progress, and is guided by a focus on combining the activity of professionals from various fields of specialization with the family’s effective, hands-on participation.

The concept and practice of “family-centered” rehabilitation has been amply discussed in the literature. The approach proposed in this book is founded on a family-based process. It is the family who will bring the relevant information and act alongside a team of professionals in all stages of the child’s rehabilitation and development.
This book contains a CD-ROM with a series of illustrated activities, to be carried out by the family, that facilitate motor, cognitive and neuropsychological development, and foster communication skills, visuo-motor coordination and independence in activities of daily life – the Illustrated Manual. The team of professionals, together with the family, can choose the stimulation activities that are most appropriate for each child. However, the objective is not to transform family members into therapists. The professionals will simply, based on their specific body of knowledge, help the parents continue their natural role of teaching the child and stimulating his development.

This methodology has been tested over the course of 27 years on more than 15,000 children with CP and TBI at the SARAH Network of Rehabilitation Hospitals. The results and the description of this approach have been published in articles and book chapters since 1983. In 2005 we published a randomized controlled trial, which studied 72 children with history of moderate to severe TBI for twelve months to test the efficacy of this family-based approach. The children were randomized into two groups, the Direct Clinician Delivered (DCD) and the Indirect Family-Supported Treatment (IFS). The children in both samples were submitted to intensive rehabilitation services for one year. Physical and functional outcomes were measured by the SARAH motor scale and the cognitive outcomes by the WISC III before and after the intervention. The DCD group was treated exclusively by professionals for two hours a day, five days a week, in a clinical setting, working in relative isolation. The IFS group was submitted to the SARAH family-based rehabilitation methodology described in this book. At the end of one year, the results confirmed that the parents in the family-supported intervention sample had developed the necessary skills for effectively delivering physical and cognitive intervention within the context of everyday routines of the child’s life at home; family education level was not a factor. Although both groups demonstrated improvement, only the children in the family-supported intervention group demonstrated statistically significant improvements in both outcome measures twelve months after starting treatment.

This randomized controlled trial study provides evidence for organizing cognitive and physical interventions and supports for children with TBI around the everyday routines of their lives, with intensive supports for their families. The results of this approach had already been observed in studies with children with cerebral palsy.

Although TBI and CP are conditions with very different characteristics, as we discuss more comprehensively in the following chapters, the family’s involvement in all of the stages of the child’s neurodevelopment has been shown to be equally important and effective in both conditions. The principles of the methodology are similar for both TBI and CP, although the application may vary, depending on the needs of the child and family within their
particular socio-cultural context. The main focus of this approach is on the child and his family, and not on his pathology.

Basic Principles: How to put this Methodology into Practice

This context-sensitive, family-based approach is structured on five basic, integrated principles that serve as the foundation for the rehabilitation program. These principles, consolidated and tested over the course of almost three decades (since the late 1970s), were co-constructed by the team of professionals and the families. The following section of this chapter will discuss these principles and provide examples that describe how to put them into practice within the daily life context of the child, family and rehabilitation team.

Principle 1: Create an individualized program appropriate to the child’s specific developmental stage in a manner that is playful, uses simple materials and integrates activities of different specialties into the same task to facilitate learning.

This approach aims at targeting the entire treatment to the specific needs of each child, with the team and the family working in a highly integrated manner. Children with brain injury manifest, in non-uniform ways, problems in different aspects of development (motor, neuropsychological, communication, visuo-motor coordination, independence, and so on). Some children with TBI or CP have more motor problems while others experience predominantly neuropsychological or communication difficulties. Consequently, various professionals are needed to work alongside the family to assess and propose activities that facilitate development.

Numerous rehabilitation centers and hospitals embrace the concept of multidisciplinary teamwork; however, these team members must often work in a relatively isolated manner. They exchange information about the child only periodically and post patient data relative to their specialty in medical charts that are accessed by all the professionals involved in that child’s rehabilitation process. The concept behind our development and rehabilitation approach differs in that it is based on a group program that integrates knowledge and experience from the professionals of various specialties. For example, if the physical therapist feels the child needs training in standing balance and the cognitive psychologist recommends exercising the mental function of classification, these two stimulation tasks can be integrated into one playful activity: while standing with front support (Figure 1.1, Activity 26), the child can play at grouping objects by two physical characteristics (Figure 1.2, Activity 71).

In one simple activity, the child can work different objectives for distinct functions, thereby constructing his development through games that target
his specific needs. When a given activity is proposed by professionals based on their knowledge of a specific area, this does not mean that the family is relegated to mere observation and passive listening; on the contrary, the family will provide important feedback about the child’s context, his capacities and interests, helping to hone each task into a targeted exercise uniquely tailored to that specific child. The idea here is that the team discuss with the family the child’s developmental stage, why they are proposing that specific activity, and listen to the family’s views on what materials would most pique their child’s interest and the ways to help make the activity more engaging and pleasurable for him.
The family is also free to give their opinion about the inappropriateness of a specific activity for their child. As the parents’ understanding about the goals of each activity grows, it becomes increasingly important to listen to their suggestions; they may have ideas about how to better perform the activity, how to make it more fun and meaningful for their child, which will lead to better results.\textsuperscript{17–19} To this end, instead of having each professional independently assess and propose an activities program, the team can make an evaluation together with the family and create the activities in conjunction with the various areas of specialization for each individual child. The illustrated exercises in the manual are then used as a group: the program is comprised of activities that integrate different areas and is adapted to each child’s reality, with the family serving as mediators of this highly individualized process.

This program uses simple household materials found in most homes and schools. This is very important, because a foundation of this methodology is the use of activities that make sense to the child’s life, are meaningful to him, and applicable to his daily reality.

The development or rehabilitation program is periodically revised. Activities that stimulate skills already acquired by the child are removed, and in their place enter new exercises that will foster the attainment of new functional or cognitive abilities and promote learning.

\textbf{Principle 2: Design a program founded on realistic, viable objectives that are based on each child’s motor, neuropsychological and communication prognosis.}

The neurodevelopment program is designed to include short-term goals that the child can easily attain. Development is a step-by-step co-construction process. Establishing simple objectives that are easy to achieve will help motivate the child or adolescent, the family and the team. Observing and valuing each small gain, then defining the next step helps facilitate development and promote integration of all the individuals involved in the process.

It is also important to have long-term goals and to be attentive to the coherence between these and short-term goals. This integration and consistency demands a detailed assessment of the child’s prognosis in each area (see further discussion in the following chapters). For example, if after the evaluation of a child with CP the team concludes that he does not have prognosis for walking,\textsuperscript{20–22} then extra emphasis must be placed on communication, cognition and schooling from the very beginning. In the case of the child who will not walk, it is beneficial to place a greater emphasis on cognitive gains, for his future and autonomy will depend on these skills. Naturally, motor functions are also worked on, and assistance from bioengineering technology to facilitate movement through mobility aids is introduced. We occasionally observe that in some rehabilitation centers, as well as in some families, there is a tendency to place more emphasis on the area in which the child is
struggling most. While it is essential to work intensively on the functions that are impaired, the areas in which the child is more capable should also be stressed for it is in these areas that he will acquire skills more rapidly and easily, increasing his self-esteem while preparing him for the future.

**Principle 3: Ensure integration of the family, child and members of the rehabilitation team.**

Since brain injury in both CP and TBI often affects many areas of development, the number of professionals involved in rehabilitation is usually large. Consequently, their integration and relationship with the family are sometimes difficult. The case manager is a clinician who has the role of overseeing, organizing, and integrating the team, family and entire rehabilitation process. Case managers can help establish a consensus within the team so that they can conduct a rehabilitation program in conjunction with the family. Our methodology works with two case managers to integrate all of the information and act as liaisons between the team and the family. Some centers work with one case manager. However, experience has shown us that the participation of two is significantly more effective because it permits an ongoing dialogue about the child and creates a situation that promotes reflection and discussion about the case by both the family and the team. This also has a practical function in that it permits the family access to at least one of the two managers should the other be unavailable (e.g. attendance at scientific events, vacation, illness, and so forth).

The case managers can be from among any of the team members (physical therapist, neuropsychologist, speech therapist, physician, educator, occupational therapist, psychologist, social worker, nurse, nutritionist, or other professionals). It is beneficial to choose the case managers based on the child’s greatest difficulties and potentials; for example, if the child’s main problems after TBI are with language but he has good cognitive potential, then a speech therapist and an educator from the team can be chosen.

The pair of managers will accompany the entire rehabilitation process, the consultations at the rehabilitation center, and periodic visits to the child’s school and home, and will call on specific professionals to lend added assistance when the situation requires it. Over time, as the child’s needs change, the team may wish to make changes in the pairing of the case managers. However, continuity of care is essential and changes should be made only after examination and consultation with the child and family.

**Principle 4: Contextualize the development program and integrate the child or adolescent into the community.**

In this family-based approach, the activities that facilitate neurodevelopment are conducted in an ecological manner within the framework of the child’s daily life. This approach creates a context-sensitive rehabilitation program
based on the child’s or adolescent’s life. Each activity selected from the illustrated manual is functional and relates to a task that has meaning for the child. When choosing these activities, the family and team considers not only the child’s present developmental stage, which is fundamental, but also the relationship between this activity and the child’s daily life, the family’s day-to-day reality, the child’s interests and motivations, and the objects and materials available at home and in school.

The acquisition of knowledge and skills, in the context of the settings, activities, and content to which the knowledge and skill apply, is more effective than the acquisitions made outside of the routines of everyday academic, social and family life. Limited transfer of cognitive training is highlighted in several cognition theories, dating back to the classic works of Vygotsky and Luria as well as contemporary situated cognition theories, situated theories of learning and standard information processing theories. Various studies have shown that when cognitive and behavioral interventions are performed within the daily routine of the child and adolescent with TBI, and when they involve the training of adults that are significant to the child’s life, the results are better. Cognitive functioning and the performance of any given task should be sensitive to the individual’s specific contexts of application and domains of relevant content.

In motor development and restoration, the neuronal group selection theory also emphasizes the environmental and action-context factors as a critical factor in motor learning.

The concept behind this methodology is integration of the activities into the child’s daily life. They should be playful and enjoyable, performed by the parents, siblings, grandparents, and teachers along with other activities that are part of the same setting. The aim is not to have a specific time and place for doing the exercises with the child, but rather that the stimulation activities be distributed throughout the day, incorporated into daily routines and habits, which will facilitate the integration and participation of the child or adolescent into the home and school environment.

The visits to the home and school by the case managers can yield much important information for the whole team and help point to the activities that are most meaningful to the child, based on the context of his life. At school, the rehabilitation professionals help the teachers by bringing them information about their assessments and suggestions about how to facilitate the child’s performance; for example, how to best position the child for writing or using the computer, the best place for an adolescent with hemineglect to sit in the classroom, etc. On the other hand, the teachers often have much to teach the rehabilitation professionals about the learning capacity, socialization skills, and behavior of the child or adolescent. The parents’ visits to the school are also of fundamental importance to the process of sharing knowledge and accompanying their child’s development, which helps promote a context-sensitive rehabilitation.