

Jennifer Niskala Apps  
Robert F. Newby  
Laura Weiss Roberts

Editors

# Pediatric Neuropsychology Case Studies

From the Exceptional  
to the Commonplace

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*To those who have always believed and encouraged, beginning with my unconditionally loving mom and continuing with my inspirational husband.*

—JNA

*For David, Michael, Kate, and Anna: Parents learn from their children.*

—RFN

*For my beautiful, resilient, compelling children, Madeline, Helen, Willa, and Thomas.*

—LWR

# Preface

For each one of us, life is a story. Our own story. It begins before we are born and is written slowly, painstakingly, a day at a time – or at some moments in a sudden flurry. Each person who touches our lives writes a bit of that story, and in turn we touch others and write bits of their stories. Our story is a collection of our experiences, evidence of our impact in the world, and the knowledge we have of ourselves as individuals. When a child comes into the life of parents, several stories unite. We imagine this union, growing up on the expectation that parenthood, and childhood, should somehow be uniquely perfect. So what then happens when an unexpected chapter of that story is introduced?

We have all heard that children are not born with a “how to” manual. No parent raising a child doubts the truth of this statement. However, for some parents, the immensity of this truth can seem difficult to bear. Some parents face the task of writing entire chapters of their child’s life while dealing with trauma, illness, and disabilities, which were never supposed to happen.

A pediatric neuropsychologist is both fascinated and frustrated by these chapters in children’s lives. For most of us, we venture into this career because of our love for children and our intense desire to help those children in need. A neuropsychologist’s career begins with training in psychology, focusing on the “normal” and aberrant development of people, behaviorally and emotionally. We then turn our focus to the cognitive functions, studying the relationship of the brain to behaviors. In pediatric neuropsychology, these diligently applied skills are used to listen to each child’s story, interpret each parent’s experience, evaluate the brain’s functional abilities, and try to find ways to guide the story’s path.

The unconditional love of a parent resonates beauty. Each pediatric professional who intervenes in a child’s life helps teach a family how to understand and grow with their child. Those of us who work in these professions know, on a personal level, how moving and amazing these stories of love can be. It is with respect to the journey children take that we collected some of those stories here.

Our intention in creating this book was to represent the incredible diversity of challenges that many children and their families work so hard to understand and overcome, while acknowledging the professionals witnessing and mediating this process. By bringing such a wide collection of stories to the reader, we offer insight into the field of pediatric neuropsychology but also into the lives of the children and

families with whom we work every day. This book is intended to inform our colleagues not only in pediatric neuropsychology but in all fields of intervention for children who are struggling, and we have attempted to include many of their voices as authors. In addition, we hope to educate students across disciplines and bring a sense of recognition to families with similar battles.

This book is divided into three sections, with individual chapters telling the personal story of a child and family seeking help. The first part presents cases of children experiencing unexpected neurological insults resulting in interruptions in their development. The second part, by contrast, acquaints the reader with children experiencing unique patterns of development. Finally, the third part presents cases that raise questions, particularly with different interpretations from various points of view and by various areas of expertise.

Each chapter, or story, is intended to both stand alone and contribute to the whole of the book. Please feel free to read selectively the chapters relevant to your interests, or start at the beginning and follow our retelling as we lead you along. An appendix is provided at the end of the book compiling all the different tests, or assessment measures, used throughout with brief explanations of how to interpret various scores. Key terms presented in chapters are defined at the end of each chapter. Some of these terms are unique to a case, while others may reoccur many times. Similarly, each chapter provides recommendations for intervention, and at times these recommendations may overlap across chapters. Much like the unique needs of the children represented here, we believe each chapter has unique needs for the presentation of information. Therefore, it was decided on a case-by-case basis, with the guidance of the authors who knew these children best, what terms, tests, recommendations, and information needed to be presented. We have endeavored for symmetry across the chapters, although we also hope the individual character of each child shines through.

This book has been an exciting and challenging project. The initial invitation from Springer Publishing to consider a book such as this left us literally giddy with anticipation. The chance to contribute something to our field representing the hard work we commit to children and families every day was both daunting and awe inspiring. All the contributing authors responded with enthusiasm as they completed their chapters, seeming to find joy in letting go of their clinical role for a brief moment, instead connecting individually with and sharing these children's stories. For us as editors and authors, we are immensely grateful to each one of you who worked with us. Your passion for each child's story is what gives this book life.

"Thank you" also to the families and children whose lives will help write the chapters of other families' stories now; to our own families, for the support and love that make our personal stories so rich; to our faithful and tireless editorial assistant, Ann Tennier, without whom this book would never have taken form: Your support and organization made reality out of creativity.

Most of all, thanks to all the students, professionals, parents, and families who work every day to create a better life for a child.

*Jennifer Niskala Apps*

*Robert F. Newby*

*Laura Weiss Roberts*



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# Part I

## Dangers of Childhood: Neurological Disorders

Children are perfect in their parents' eyes. Although parents may know their children have flaws and weaknesses, their children complete them in a way that often blinds parents to those qualities. Parents' love for their children is so strong and absolute that they forget all else. They defend their children fiercely and protect them passionately, and when their child is injured or hurt by something outside of their control, parents can be overcome.

This section presents a series of cases in which children experience unexpected deviations in their otherwise normal development. Their parents are often beset by the severity and enormity of what has happened. Each parent's question to the pediatric neuropsychologist is slightly different. Some are not ready to hear what their child now needs, while others cannot get the information quickly enough. In every case, managing the child's and the family's needs is a delicate balance.

This section opens with a chapter about premature birth. According to the March of Dimes Web site, <http://www.marchofdimes.com/>, premature birth is the number one obstetrical complication in the United States. For parents first meeting their new child, prematurity adds a stressful and frightening chapter to their story.

The next four chapters describe children experiencing head injuries from different circumstances. The developing brain can be injured in various ways, with a range of short and long-term sequelae. According to the Centers for Disease Control Web site, <http://www.cdc.gov/ncipc/tbi/TBI.htm>, brain injuries are the leading cause of death and disability in children and adolescents. Further, one-third of all pediatric injuries involve some form of brain injury. The causes of these injuries vary greatly by age and ethnicity. Under age 5, falls are the most frequent cause. Motor vehicle crashes are another common cause of these injuries. Mild traumatic brain injuries (TBIs) can occur with concussion, either because of injuries or sport-related activities. Of children under age 14, an estimated 475,000 TBIs occur each year, and children under age 4 are at highest risk. In addition, brain injuries in infants are a particular concern when they result from Shaken Baby Syndrome. Although it is difficult to estimate the prevalence of this trauma, the National Center on Shaken Baby Syndrome approximates that 20% of infants presenting for medical care with these injuries will die, with the majority of the survivors having permanent brain injuries (<http://dontshake.com/>).

The following seven chapters present children with medical illnesses disrupting their development and resulting in neuropsychological sequelae. Many acute and systemic medical illnesses can have long-standing impact on the developing brain, resulting in neurological trauma. The National Cancer Institute reports that just over 3 of every 100,000 children will be diagnosed with some form of brain cancer (<http://seer.cancer.gov/publications/childhood/>). Not only can the experience of cancer itself result in neurological insults, but the treatments used for cancer, including radiation and chemotherapy, have documented long-term effects on a child's mental capacities.

Seizure disorders also cause neurological insults for children. According to the Epilepsy Foundation (<http://www.epilepsyfoundation.org>), each year 120,000 children under age 18 years will experience a seizure and 45,000 children will develop epilepsy. At any given moment 326,000 children in elementary school and junior high school have epilepsy. The neurological impact of this illness can range from mild to severe, depending on the location and type of seizure activity, seizure frequency and severity, and the medical interventions used to treat the seizures.

The last two of these seven chapters highlight the impact such difficulties can have on families. When a child experiences an illness or injury, particularly a life-threatening one, the dynamics of the family change. Parents work to protect and conserve their family's identity while focusing on making things "better." As neuropsychologists, we often must address the family's needs in addition to the child's cognitive, social, and emotional needs. Chapter 11 particularly highlights the interaction between neuropsychology and therapy. Chapter 12 also touches on the complications of the family's vs. the children's needs, while presenting a different etiology of developmental disruption.

Chapters 13 and 14 relay stories of children experiencing more unusual accidents. Although many childhood accidents result in direct brain injuries, some result in indirect neurological insult. In these two chapters, injuries to the child's body, through physical injury in one case and anoxia, or lack of oxygen, in the other, resulted in long-term neuropsychological sequelae. For some families, making sense of why such apparently random accidents happened to their child is perhaps the hardest part.

As you read each chapter, you will find several tools to assist in your understanding of the information provided. Key terms are in bold face at their first use and defined at the end of the chapter, where references for both clinicians and families are also provided for those wanting more information about the condition(s) presented. Test scores from neuropsychological evaluations are provided in tables. The appendix at the end of the book lists the tests and describes normative test data and standardized scores.

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