

# Preface

In her 1987 essay entitled “Welcome to Holland,” author and social activist Emily Perl Kingsley recounts her experience of the 1974 birth of her son, Jason, with Down syndrome. She described her pregnancy and anticipation of childbearing and the impact of learning her child had a lifelong disability. She says it was like looking forward to a lovely trip to Italy, where she had dreamed of being all her life, but landing in a totally different place, with a totally different language and surroundings. The experience of rearing a child with special needs in a community of typical families is akin to watching fellow travelers enjoy going to and from Italy and saying to them, “Yes, that is where I planned and wanted to go, but we landed somewhere else.” Jason Kingsley grew to become an actor on *Sesame Street* and other shows, and Emily Kingsley’s essay ends with her affirmation: “But . . . if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things . . . about Holland.”

A statement by Uncle Abner in one of Mark Twain’s stories spoke of how one gains experience.<sup>1</sup> It has been commonly paraphrased as: “A man who carries a cat by the tail learns something he can learn in no other way.” My cat is Melanie. In 1979 our beautiful identical twin daughters, Melanie and Melissa, were born. After noting some delays in Melanie’s development compared to Melissa, our pediatrician recommended when they were around one year of age that we get a more in-depth evaluation. The pediatric neurologist conducted numerous tests, observing her physical and cognitive responses. The diagnosis was a hammer-blow. Cerebral palsy. In shock and fear, we began to do what all other such parents do—we researched. We learned that cerebral palsy, or CP in the vernacular, can manifest in mild, almost unnoticeable spasticity in a hand or leg or other part of the body, or it can result in severe cognitive, mental, and physical limitations requiring full-time total care. And like every other family who has no crystal ball and cannot see the future, we had no idea which direction we were heading. Like those other parents, we began the process of identifying and developing a network of professionals to help us—pediatrician, pediatric neurologist, physical and occupational therapists, pediatric ophthalmologist, speech pathologist, early intervention specialist, and later, orthopedic surgeon, urologist, and a host of vocational and educational rehabilitation

<sup>1</sup> *Tom Sawyer Abroad*, Samuel Clemens, 1894.

specialists. Melanie had seven neurologic and orthopedic surgeries in her first 10 years of life. Through that time and since, we have admired her spirit of independence and ability to come through adversity undefeated. She is a spirited young woman who, though reliant on family and independent caregivers for assistance with some daily tasks, is an educated, working, tax-paying citizen.

But it isn't all about Melanie. There is the family, and dealing with the rigors of managing a disability takes a toll. As parents, Ruthie and I watched to see the effects of her sister's struggle on Melissa. While they have from the beginning been each other's biggest cheerleader, the disparities in physical and educational achievements put some distance between them in terms of social circles, recreational activities, and other areas that typical twin sisters would have in common. We observed, sometimes in hindsight, the emotional stress on Melissa from seeing what her sister was going through and being helpless to make it better. Siblings pay a price. However, through her own internal strength, spiritual faith, and determination, Melissa—the "little sister" by two minutes—has become an adult help to Melanie, and her teenage sons love Aunt Melanie's service dog and think her power wheelchair with elevator is awesome.

And, do not forget the parents. Our "trip through Holland" has been arduous, exhausting at times, frustrating, and at the same time a revelation of the human spirit in all people and a galvanizing force in our marriage. We have celebrated the achievements of both our children, and we have worked to provide them with opportunities designed to stretch their imaginations and challenge their physical abilities. We have determined to seek each other's ideas about how to handle problems that arise, collaborate in carrying out solutions and strategies to address them, and enjoy the times of calmer seas when they arrive. Alone time is vitally important for parents or full-time caregivers of a person with a disability. As we get older, we are feeling what so many of my clients express—a desperate uncertainty about what will happen for our child when we are no longer here or able to help. There is a dearth of residential, transportation, social engagement, and other services for persons with developmental disabilities in our and many other communities. When the day-to-day strain of dealing with all the disability-related work subsides from time to time, we can support and continue to look for services and opportunities that will enrich our daughter's life, now and in the future. And we can develop a financial and legal plan to provide for her future financial and care needs and execute the necessary wills, trusts, powers of attorney, letter of intent, and myriad other documents necessary to implement that plan.

There is a forest of public and private resources, organizations, and assistance programs for people with CP and other acquired and developmental disabilities. The first step for parents like us is finding the ones that can help. That is no easy task. Soon after Melanie's diagnosis, we began looking for financial

help to pay for physical therapy and other medical expenses. The answer we heard most often—and the answer many of our clients have heard—was “No, she is not eligible because [she is too old/she is not old enough/your family has too much income/you have too many assets/there is a waiting list for those services].” After dedicating months to research, we found out that the answer was actually “Yes, there is a Medicaid program that can help with those things.” This frustrating interaction with bureaucratic public assistance programs is a recurring theme today.

That is why I am a special needs attorney. Were I not a special needs attorney, I would be looking for one to help my family traverse this challenging landscape. There is a great need for such attorneys today. During the Great Recession that began in 2008, our law firm did not experience any downturn in special needs client work or revenue. The reason is that families who desperately need help solving the problems for their disabled loved ones will make that a priority, and those attorneys who have established their ability to help with those things will find those clients coming. It is my hope and aim that this book will equip the attorney who has not yet invested a career in special needs law to assist those clients to understand their options and devise solutions, and even to encourage the reader to pursue this needful and rewarding practice.