

CASE STUDY Cerebral Palsy: a History of a Functional Neurological Approach

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These case studies, each submitted by a Certified HANDLE® Practitioner, demonstrate outcomes achieved through implementation of an individualized HANDLE program. The acronym stands for the Holistic Approach to NeuroDevelopment and Learning Efficiency. The HANDLE paradigm for understanding behaviors and their root causes is thoroughly explained in *The Fabric of Autism: Weaving the Threads into a Cogent Theory*, by Judith Bluestone, the creator of HANDLE and the founder of The HANDLE Institute International, LLC in Seattle. For intimate insights into client and family experiences of HANDLE, see *The Churkendoose Anthology*, with commentary by Judith Bluestone.

For each of the clients in these case studies, the practitioner began with a comprehensive assessment, the findings of which led to a Neurodevelopmental Profile, which in turn formed the basis for a program of activities complex in their neuroscientific premises and very simple to implement. Thereafter the client's program was modified about monthly in accord with changes achieved in the interim. Each client participates in twelve to fifteen activities regularly; the practitioner, in writing up the case study, names those activities in brief without the full details and explicit information each client-family receives in why and how to implement the program. Go to www.handle.org for more information.

Note: In this case study, neurological chiropractor and certified HANDLE practitioner Dr. Bonnie Hayes tells the personal story of her brother Patrick. It departs from the usual case study format in order to allow her to fully share this unique experience.

My brother, Patrick Sawyer, was born August 7, 1950. He was the younger of identical twin boys born at term in a natural childbirth. The doctors had no idea that my mother was carrying twins because they had a simultaneous heartbeat. The larger twin weighed 7½ lbs. and Pat weighed 6½ lbs.

Pat spent the first six or eight weeks of his life hovering between life and death in an incubator. Born with hyaline membrane disease and cerebral palsy the expectations of his survival were slim but the determination and strong will that were to mark his life were evident even in his earliest days. Pat was a fighter and his strong spirit helped him to survive when hope for his survival was slim to none.

Patrick was the third child of Frank and Eleanor Sawyer who lived in post war Birmingham, Alabama. Frank Sawyer was a 43-year-old accountant who had served in army intelligence in World War II.

Pat's mother, Eleanor Sullivan Sawyer, was trained as a social worker and later as a grade school teacher. At the time of Pat's birth, Eleanor was 36 years old. Pat's parents lived in their own home with their first child, a daughter, Bonnie who was almost four years old at the time of Pat's birth.

The birth of Frank's and Eleanor's second child was eagerly awaited by both parents and the entire family. Eleanor suffered a great deal during the last months of her pregnancy. She was unusually large and her feet and ankles were monstrously swollen; the doctor reassured her that she was going to have "a large boy." Words like pre-eclampsia and bed rest were never mentioned, although she often reclined due to the discomfort in her feet and legs.

When the twins were born, they were delivered at St. Vincent's Hospital in Birmingham. The first twin was delivered with no difficulty. The doctor, realizing that there was another child far up in the

womb, reached in and pulled out Pat. He was blue at birth and was immediately given oxygen.

Pat was in the newborn ward for weeks after birth in an incubator. I knew from the worried looks on my parents' faces and the angst that permeated our home that something was very wrong. One of my first memories is of being taken to see my baby brother in the hospital. My parents wanted me to see him because they did not expect him to live. In those days children under 12 were not allowed in hospitals unless it was a matter of life and death.

Because I was so young at the time some pieces of family history were relayed by others. For example, my uncle relays that there was strong pressure put on my father and mother to institutionalize Pat early on by my grandfather. My grandfather, William Sullivan, was a very strong-willed paterfamilias who expected to be obeyed. He had been a very successful businessman in an era when Irish people were greatly discriminated against. He was determined that my parents should quickly put Pat away.

My father, Frank, an equally strong-willed Irishman, refused. My mother, who was incredibly tender-hearted, fell immediately in love with Pat. So Pat came home when he was able and both parents cared for him, his normal twin and me.

Health History

Pat was born with hyaline membrane disease and cerebral palsy. His early life was marked with numerous infections and fear for his life. He had difficulty sucking from a bottle and often frightened my parents when he choked while sucking.

Pat did not walk or talk until he was between four and five years old. By four and a half years of age he was speaking. He began speech therapy early, certainly for that time, and continued until he was eight years old. In time his speech improved, but there was always some difficulty being understood by others. Pat, however, learned to be very attentive when others spoke. He acquired an extensive vocabulary and expanded ability to communicate highly complex subject matter. Along with that he also developed a wicked sense of humor that he uses in social gatherings. Anyone who invests the time to find out what Pat is thinking or feeling about things will be rewarded for his efforts. Pat learned to hold his own in social gatherings and

will focus on what others are saying and respond with cogent and often brilliant repartee.

My mother investigated everything she could find about cerebral palsy and discovered that one of the world's authorities at the time, Dr. John Simpson, a pediatrician, had a clinic in Homewood, Alabama, a suburb of Birmingham. Pat was taken to the clinic to be evaluated and our family began our adventure in helping Pat.

In the beginning of his program, Pat was patterned along the lines described in the works of Doman and Delecató. Most evenings at our house were spent crawling, creeping and moving Pat's arms and legs in cross-crawl pattern. My recollection is that the patterning worked quickly for Pat and he began developing pre-walking skills very soon after beginning the patterned movements. Once he began to see that he could stand with assistance, he would make attempts to take steps. The whole process of learning to creep, crawl, stand with assistance and walk with assistance took about two or three months. He caught up very rapidly once his brain had the right neural patterns activated by the patterning.

Independent walking, took awhile after that, but only a few months. I remember the elation we all felt when he crackled with glee at making his first independent steps. After that the puck and grit that have so characterized Pat throughout his life came into play and he made rapid strides in walking. He was determined to keep up with his twin brother and the other neighborhood boys as much as he could.

Pat has retained the classic scissor gait of the cerebral palsy throughout his life. He has compensated by developing a great deal of strength in his arms and legs.

Pat had made so much progress that Dr. Simpson encouraged my parents to put him into a regular classroom as he approached school age. Pat did well there and was then encouraged to go to a regular classroom for first grade—which as it turns out was another story.

Pat started first grade at the local parochial school. In those days, Catholic schools were very crowded affairs and there were about 60 children in his first grade. The nun who taught him was very young and not prepared to have the additional stress of

a moderate to severely handicapped child to deal with in her classroom. She made life very difficult for Pat. This went on for several months, when the final straw happened. Pat followed some of the older boys to a far corner of the playground. Pat had toilet control for several years before entering first grade but that day in his desire to keep up with the other boys, he had overextended his ability to retain and had an accident. The nun was furious and locked Pat in the bathroom that adjoined the classroom until it was time for dismissal.

My parents were mortified and withdrew Pat from the Catholic school and placed him in a small public school for the remainder of first grade. From second grade through sixth grade he attended a small private Catholic school in a classroom with about 12 to 15 students.

With the approach of adolescence, many changes began for him. Not only was he going through the typical hormonal and growth changes but his awareness of himself as a person with a lot of challenges became greatly amplified. He began having crushes on girls and attempting to form the pre-boy/girl relationships that characterize that early adolescent period. He began having a very great internal struggle with reconciling himself and his limitations with the world in which he lived. As a result, my parents removed him from the small private school after sixth grade and sent him to the cerebral palsy school, the Charlann School in Birmingham .

Pat did well at the Charlann School but never really identified in his core reality with cerebral palsy. He was a person with cerebral palsy not cerebral palsy. At Charlann Pat began to reconcile himself more with his limitations as he learned and interacted with other children who shared his issues. Pat left the Charlann School at 17. He then took the GED test in lieu of completing a typical high school program. My father coached him and helped him learn the subjects that were not offered at Charlann.

After receiving high school equivalency through GED, Pat attended college classes at Jefferson State College and at Samford University. He was unable to write and take notes so he taped his classes. In those days there were no personal computers let alone lap tops that most students at the college level have now. Computer technology would have

been an incredible boon to him. He was later to learn how to use a computer with certain adaptations to the computer. My father continued to tutor Pat at home and he and my mother helped him with typing papers. My father bought an old upright punch-key typewriter for Pat and Pat wrote many letters and papers with it.

The keys on that model of typewriter were difficult to punch and well suited to the continual overflow of movement that Pat has in his fine motor finger movements.

Pat wanted to learn to drive a car like all teenagers and drive he did—albeit with fear and trepidation on the part of my parents. Not only did he learn to drive but he learned to drive a stick shift. Pat has fairly good large motor control but prefers an automatic because it is less energy expensive for him.

Pat has now been driving for 40 years and has had very few accidents. I have ridden with him many times and know that he is an able driver. I have felt safer with him than with many less-challenged drivers.

After attending college classes for several years, it was time to consider what Pat could do to earn his way. My parents were older when Pat was born and the subject of whether Pat could provide for himself in any way or how to help him to survive in the big world weighed heavily upon them. Pat's old friend Dr. John Simpson came to the rescue and suggested that he apply at University of Alabama Medical Center. Through the largesse of Dr. Simpson's recommendation, Pat was given a job at UAB Medical Center in medical supplies.

Pat worked at the UAB Medical Center for 25 years and retired. He worked a 40-hour week and sometimes did overtime if he was needed. He often worked holidays so the other employees could spend Thanksgiving, Christmas or New Year's with their families. Pat became a well-known person in Birmingham, as he pushed his cart down the corridors and labyrinthine passageways of UAB Medical loaded with medical supplies. His scissor gate, labored speech and titubation of the head distinguished him many feet away.

Pat developed great compassion at UAB as he saw so many ill and suffering people. Whether because of that or because of his unexpected presentation in that setting, it was very common for people to

speak to him and tell him what an inspiration he was to them. They would say, "If you can do it, I can do it."

At home things continued on about the same for quite awhile. Pat continued to live with my mother and father who provided the framework that enabled him to function in the world and at work. He exhausted most of his energy working and for the most part did not do his daily upkeep such as laundry or meal preparation for a number of years. Things began to change when my father got ill with cancer in 1984. He needed care and Pat took on some of that responsibility. Frank Sawyer died October 1984 leaving a large gap in the fabric of the daily life of Pat and my mother. Pat and my mother continued to live together for the next 17 years. As my mother declined physically and became progressively less able to do household duties and then later began to decline mentally, Pat began taking up much of the slack. He learned to do laundry and cook, and took on the grocery shopping and yard care.

After my mother passed away in 2001, Pat continued to live in the house he grew up in. Since then, he has lived alone. He returned to work at UAB as a pharmacy technician. He was thrilled to get this job and his remarkable memory which no doubt he has developed in response to the difficulty with reading, has served him well. It is challenging and interesting to him with much better pay. Pat also began a very active social and community life after my mother's passing. He became involved in his church community and does a lot of volunteer work for them. As Pat found his place in life, he developed a fulfilled and happy life by himself. He leads a full life by most standards.

HANDLE

Pat's introduction to HANDLE was about four years ago. I had attended a Get A HANDLE on Neurodevelopmental Differences Introductory Class presented by the late Judith Bluestone. I was so moved by what I heard that I was transported back in time to the point when we were doing similar activities for Pat as a very young child. I had the advantage of a lifetime of seeing the outcome of doing neurodevelopmental functional activities on a person with moderate/severe cerebral palsy. A lot of missing pieces fell in place for me that weekend as I began to see the relationships, comparing what I had experienced in the distant past

with the far more developed approach presented by Bluestone. It was a deeply moving experience as I saw and felt what was available through the HANDLE approach, knowing what I knew and seeing the impact of the now Paleolithic version of a neurodevelopmental approach from 50 years past on the life of my brother. I know that he functions at a level far higher than any reasonable assessment would have given him then or now. As a result of that weekend I resolved that Pat would have the opportunity to receive the HANDLE work himself if he was interested. Little did I know that he would enthusiastically embrace HANDLE.

Pat began by attending an introductory class. He wanted a deeper understanding of the work and that weekend he got it. Then he took the information he received and began working with it by applying it to himself. As he did, he began to get results. The main thing he noticed was a greater sense of his own presence. What I noticed was that he seemed calmer, clearer, far less agitated and irritable with a decrease in the degree of fine muscle tremor he has in his trunk and hands. He had only been doing the Skull Tapping activity daily which he could manage by himself.

Pat repeated the Get a HANDLE class the following year. By this time he had learned all of the material but only did one activity with any regularity. Since he had been doing only the Skull Tapping activity daily with such good results he agreed to do an evaluation.

Pat was hoping to have whatever improvement he could from an expanded workup. He really didn't know exactly what to expect but was pleased with his earlier changes. He was evaluated in the spring of 2007 by HANDLE Intern Valerie MacLean in Atlanta, Georgia. I was present during the evaluation.

His evaluation was an interesting experience for him, a real journey in self discovery. He discovered that his various systems were compromised from the HANDLE perspective. This included his vestibular system, tactile system, proprioceptive system, kinesthetic system, oral motor and muscle tone. These weakened systems were undermining his further neurological improvement. HANDLE gave Pat a doorway to help himself. Particular emphasis was placed on the challenges of his vestibular system as the cornerstone of his further improvement. Each HANDLE program is given

specifically for that one individual to meet his particular needs and concerns. Ergo, Pat who has very perceptible balance problems was encouraged to know there are ways to improve his vestibular system and therefore his balance as well as the systems that HANDLE describes as being supported by the vestibular system.

Unfortunately due to many circumstances Pat was unable to return for follow-ups to his program. Since I was a HANDLE Intern at the time, I was able to help him to some extent, but we both regret he was unable to match up times with his work schedule for the refinements to his HANDLE program that are a big part of program success.

Outcomes

Pat had immediate changes as a result of his program. Since he lives alone and at a distance from me, he was given a program that was suited to him that he could do for himself at home. He was reluctant to involve friends, family or neighbors. He is very committed to being as independent as any other person and therefore seldom asks for help unless absolutely necessary.

He and I talk frequently on the phone since distance is a barrier. Not long after starting his program, I noticed that his speech had improved on the telephone. I asked him if he had noticed it. He said he had and that others had mentioned it as well. He seemed to enunciate more clearly and his cadence was improved.

Before starting his program he was slightly stooped in order to balance. The next time I saw him I noticed he was standing up straighter. He was holding his head erect for the most part even when walking. He said he had noticed that as well and he had not fallen since he started his program. After that falls became quite rare for him, a great help for him since he is a six foot adult male weighing 185 pounds and now in his late 50s.

Pat also shared that his shoes were lasting longer. When he walked his feet would brush the ground due to his scissor gait. The outside soles of his shoes would wear out quickly and even good-quality athletic shoes would need to be replaced very often. Interestingly enough, even the wear pattern on his soles changed from the outside of the soles to the middle of the soles, a real indicator of improved balance, muscle tone, proprioception and kinesthesia.

The most amazing result Pat had from his HANDLE program was his left hand. His left hand had been “turned off” since birth. He had gross motor but not fine motor control in his hand. He gained fine motor control in his left hand within a few days after starting his HANDLE program. He was thrilled! He could hold his knife and fork and cut meat all at once without having to ask for assistance again. This one thing socially liberated Pat. Now he could go out to dinner in public and eat steak with his peers and not be dependent on anyone. His confidence level soared!

Updates

Due to the complications of his cerebral palsy, one of his concomitant conditions was GERD which developed into an esophageal cancer. Pat underwent surgery for the removal of his esophagus and resection of the stomach to what remained of his esophagus in early December last year at the University of Alabama Hospital. He survived surgery and appeared to be doing well when he developed pneumonia. He was admitted to ICU where he was a resident patient for about five weeks surviving pneumonia and a relapse of pneumonia. He was then released to a regular hospital suite unable to talk, swallow or walk. He was either shut down, turned off or simply too weak to stand without collapse.

After two weeks in a regular hospital room, he went to Spain Rehabilitation Center at UAB—an excellent facility for his needs. Pat spent about two months there and regained the ability to speak and to walk. He was walking on his own to the bathroom and somewhat around the hall when he developed another life-threatening infection that resulted in considerable weight loss due to dehydration from diarrhea. Once more, Pat had to learn to walk. He has soldiered on and is currently in a secondary care facility where he continues to receive intense speech, physical and occupational therapy. He plans to go home with assistance and it looks very hopeful that he will be able to return home within several months.

At different stages in Pat’s long recovery he has used some modifications of his HANDLE program to assist his function and smooth recovery. He has been able to do them in his hospital room by himself. While he was in the ICU, I was able to assist him at key times using HANDLE. Pat’s prognosis is good at this point for his return to his normal life

over time. He is anxious to go home and to return to work and his active social and church life. No doubt with time his determination will get him there.

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The Churkendoose Project presents these case studies to demonstrate the successes of the HANDLE approach and pique the interest of researchers and funders in engaging in clinical studies to further examine the efficacy of these interventions. For more information about The Churkendoose Project, go to www.churkendoose.org or email us at info@churkendoose.org. You can email us to obtain pdf copies of these case studies.

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