

RIDING THE GIRAFFE: A SOCIAL WORKER'S NINE YEAR JOURNEY

This narrative recounts my work with a family of a mother, and her two sons over 9 years. The oldest child had a rare developmental disability known as Wolf-Hirschhorn Syndrome¹ In this story I explore the different ways I tried to assist the family in supporting their adaptive capabilities in the context of many setbacks and challenges. This personal account describes my own success and failures over this 9 year relationship. At times I questioned my ability to help them as they faced so many obstacles. The family's energy to advocate for their child continually restored my confidence that I could make a difference in their lives. Nine years is a long period of time to be doing social work with a family. It's unlikely that it could occur today.

By Lonnie R. Helton

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BEGINNINGS

As a clinical social worker I worked for eleven years with families whose children had developmental disabilities. Some parents experienced great difficulty in coping with their children's complex physical and mental disabilities; while others tried to deny the severity of their children's problems. However, I am amazed at how most family members, especially the siblings, faced the rearing of such children with boldness and resilience. Although many brothers and sisters of children with special needs at times felt left out, competed for their parents' attention, or took on surrogate parenting roles; others were strengthened by having such a sibling and achieved remarkable personal growth.

I remember this family, in particular, as one of my most challenging cases. I learned from them about the intense and pervasive needs of families with a disabled child, and about myself as a professional helper. This was my longest involvement with a family—over nine years; and the child's disabilities were the most unique of any on my caseload.

When Nell Barton was referred by the attending pediatrician for "intensive counseling" at

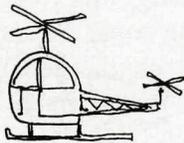
the Developmental Center, I did not know what to expect. I worked as a family evaluator and field practicum coordinator and had no openings for counseling. Dr. Goldberg described the Barton family as a divorced mother struggling to care for her two young sons; the mother was especially challenged by Kevin, who had Wolf-Hirschhorn Syndrome.¹ As Dr. Goldberg described the developmental disorder, I questioned whether I was up for the task, but agreed to counsel the mother. I could see the relief on Dr. Goldberg's face as she walked away. The medical library did not offer much help. I spent as much time looking up specific clinical descriptors of Wolf-Hirschhorn Syndrome in the medical dictionary as I spent reading about the syndrome itself. Nor was there anything available on how to approach the families of these children, most of whom died at a young age.

Initially I saw the whole family together — Mrs. Barton, age 31, and her sons Kevin, age 6, and Steven, age 3. Kevin, non-ambulatory and legally blind, functioned developmentally at a 10 month level. They appeared to be a close knit family but since the mother's stress level was 'off the scale,' I decided to attend to her

¹ First discovered in 1965, Wolf-Hirschhorn Syndrome (a.k.a. Wolf's or 4 p- Syndrome), a genetic disorder caused by partial deletion of chromosome number four, is known, to this date, to affect only about a hundred children in the entire world (Katz & Smith, 1991). The characteristics of children with Wolf-Hirschhorn include: severe mental retardation; small head; delayed physical growth; cleft lip and drooling; moon face, low-set ears; severe visual disabilities; seizures; low immunity for respiratory infections; clubfeet and bone deformities, poor coordination, severe heart defects, urological problems, and other anomalies (Wolf, 1965).

immediate needs.

Early on she noted that she tried hard to foster closeness between her sons despite the ever increasing gaps in their developmental functioning. She would tell baby Steven about his brother's disability, always adding, "but we love your big brother more than anything." Years later Steven could recite what his mother had been told by the medical specialists. Although he remembered that there were only a handful of children in the world with problems like Kevin, he demanded to have his fair share of her time.



Later I saw Steven separately for play therapy. Active and mature for his age, he liked to fly his toy helicopter around the room and position his "he-man" toys near my desk or bookcase. He looked forward to these sessions and absorbed all the attention I provided.

When I mentioned Kevin and his mother, he appeared disturbed about his brother's disabilities and did not understand why his brother had to see so many doctors and undergo physical therapy. The "facts" had become jumbled in Steven's head. He understood that his brother had "special problems" and had tried to explain this to the other children. As he grew older he said that his best friends usually understood, but not always. Steven told of an incident wherein an-

other boy had yelled "retard" at Kevin and he ran after the boy yelling insults until his mother tried to calm him down. I thought it might help to have a joint session so that Steven could have a chance to talk about his experience. Mrs. Barton said she did not want Steven to think that fighting resolved such a problem, let alone make it go away. As his mother spoke, Steven played with his "He-Man" toys. This time he positioned the small figures close to the stroller where Kevin had fallen asleep.

As Steven became accustomed to play therapy, he asked specific questions about his brother. "Would he ever be physically larger and able to do chores?" I reached for feelings of resentment toward his mother for expecting him to pick up his clothes, take out the garbage, and watch his brother. He said he wished Kevin were not "such a baby" and could help him with his chores. Realizing that siblings of special children often feel that they lack a distinct role within the family, I encouraged him to teach his brother to do simple things that he could himself do well.

Later in a joint session Mrs. Barton described Steven as her "little man of the house," and Steven responded with, "but I just want to be like the other kids." I encouraged Steven to tell his mother how he felt he was different, and what he had said about the chores. After a moment, he replied, "I have to watch Kevin when you are cooking' and stuff... and I want to take a bath by myself." Mrs. Barton acknowledged that she had not known that he felt that way and made him prom-

ise to tell her when he felt sad or angry about such things. He agreed but was uneasy about having revealed his emotions. I said although it was difficult talking about thoughts and feelings, it could help him feel better.

Mrs. Barton acknowledged she used Steven as a "baby-sitter" but had not intended to burden him. With some uneasiness she added that she would run short errands to the grocery store or to her friend's apartment because she trusted Steven to watch Kevin—elaborating on what a "blessing" Steven was. I felt bad that Stephen was used this way and anger with Mrs. Barton for her poor judgment; I tried to persuade her not to encumber Steven with responsibilities beyond his capabilities. As Steven heard this he climbed on his mother's lap and hugged her. Mrs. Barton listened with tears in her eyes, as we talked about alternatives for child care. Occasionally she used the county's respite program but had reverted to a pattern of trying to make do on her own, that is, with Steven's help. I advised her to use respite services more regularly and to apply for child care through the Medicaid waiver program.

MIDDLE

Subsequently I spent more time talking with Mrs. Barton about her feelings of depression and her internal struggle to be both "mother and father." She blamed herself for the divorce, for never "doing anything right." Wondering why she had such a compelling desire to be perfect, she ex-

panded on her "mistakes." She went on to say that she should have been able to handle the demands of raising a child like Kevin and have maintained the home to suit her husband.

As we discussed these feelings in depth, Mrs. Barton avowed that it was largely her fault that she and her three siblings had been placed in foster care. I felt that we were getting closer to the roots of her discouragement. She had trusted me with major expressions about her ex-husband and was angry that they could not communicate about Kevin's care, yet she held back when questions centered on her own childhood and family of origin.

With many tears she told that her father had sexually molested her when she was a teenager until she reported the abuse to a trusted high school teacher. At that point the family disintegrated. Although Mrs. Barton later discovered that her older sister had also been sexually abused, she blamed herself for the placement of herself and the remaining children in separate foster homes. Her mother had left several years before the abuse report, perhaps having suspected the father's actions. This revelation shed some light on why she had to be the ideal parent. She seemed to want to make amends for the flaws in her own parents and her ex-husband who had also deserted his children.

When Kevin was nine, Mrs. Barton's younger brother, living in Hawaii, invited her to come for a two-week visit, all expenses paid. She was reluctant to leave Kevin and Steven with a re-

spite provider, and anxious about such a long visit with her brother whom she had not seen since the family breakup. I thought the visit might give her an opportunity to renew family ties and explained that the time away from the children might be beneficial and give her time to think about just herself. She disagreed and declared she never saw herself outside of her parenting role. Impatient, I struggled to convince her to take the trip. I could not believe that she would let this opportunity slip by. Finally, she agreed.

something just for herself. This betrayal signaled rejection by a significant person once again.

At her next session, there was a sense of renewal, in both body and spirit. She had lost weight, changed her hair color, and was very cheerful. Mrs. Barton thanked me for having strongly encouraged her to do something for herself.

When Kevin turned ten he surprised his teachers, school therapists, and especially me. He had always been pushed into my office by his mother or Steven in a special reclining stroller. But the



The week before her departure, her boyfriend of several years told her that their relationship was over, and that he had found someone else. Distressed, Mrs. Barton canceled the trip. Again, we discussed the benefits and ultimately she decided to go. I felt that the incentive to distance herself from her ex-boyfriend was at least as great as her plan to do

week of his tenth birthday he "defied all records." The little boy with Wolf-Hirschhorn Syndrome, who had an original life expectancy of three to six months, walked into the office on his own two feet and threw himself on my lap, laughing out loud. Steven laughed too and hugged his brother. Mrs. Barton, stood with tears streaming down her

face...repeating, "I never stopped believing. I just knew he would do it." While we celebrated Kevin's newfound mobility. Mrs. Barton recalled how an orthopedic surgeon had once told her that correcting Kevin's clubfeet would be futile since he'd never walk. And, that the ophthalmologist had recommend against eye surgery because of the uncertain benefits to Kevin. She had refused to hear the word "no," as she had many times before when Kevin's surgeries were labeled "optional" she had gone ahead with the surgery.

Two weeks later I worked again with Steven in play therapy. At first he wanted to play with his favorite helicopter in front of the window, then agreed to draw three pictures with a red crayon. One picture depicted a little boy sitting on a giraffe. The picture was labeled simply "geraffe." When I asked Steven to explain the picture, he said the boy on the giraffe was Kevin and that he was riding so high. I thought that the drawing of Kevin riding the giraffe symbolized Steven's high hopes for his brother.

In years to come, all of us remembered that moment and Steven's picture of the giraffe. Meanwhile, Kevin continued to progress and by the end of his tenth year, according to his mother, was able to say more words, had fewer seizures, and had improved his feeding and hand coordination skills. Occasionally he signaled his mother that he needed to potty, by walking toward the bathroom. He liked getting the family and neighbors' attention by mimicking the prelude to commercial

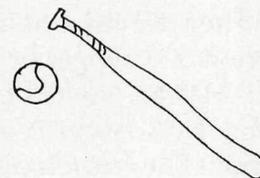
breaks on television, "I'll be right back." Steven laughed with glee when his brother's antics brightened his mother's face. For a time it seemed as if Kevin's walking instilled in Steven a false sense of hope that other age-level skills would follow suit. I encouraged him to anticipate smaller, long-term changes in his brother's abilities.

Kevin's resilience ironically resounded through each eye surgery, urological procedure, and bout of pneumonia...and each time he yelled out, "I'll be right back." There were moments, however, when Steven became silent and assumed a sad, pensive look. He was continually reminded that his brother was different from most children. He was especially chagrined by an incident at the local YMCA where the family had been given an athletic club membership by their church. His brother was left in the day care unit with the younger children until one mother complained to staff that this "large, unusual child" might hurt the other children. With my encouragement and support, Mrs. Barton who had always been a strong advocate for her son, took the issue to the YMCA Board, but the controversy was only partially resolved. The YMCA located another mother of a child with disabilities and suggested that the two mothers supervise each other's child in day care and take turns working out. But, after awhile the mothers' schedules conflicted and the Bartons quit attending the YMCA.

Steven talked about how unfairly his brother was treated; he sometimes felt that he too was victimized because of Kevin's

problems. Although Steven played T-ball at school, he seldom stayed after the games to talk with friends because his mother had to get the them back home, to give Kevin his medicine or administer oxygen. His father re-married, had two sons within a two-year period, and made it clear to Mrs. Barton that he did not feel comfortable having both boys visit him. Steven said he enjoyed being alone with his father but wondered if his father was upset with him. He had overheard his father and grandmother say, "Steven does not deserve to live in a handicapped home." I told him I did not think this to be the reason and suggested that perhaps later he would be able to see his father more often. However, the parents continued to fight about visitation and visits stopped abruptly when Mr. Barton told Steven to stop "disturbing" the family with his phone calls.

I continued to see Steven in individual sessions, although these became less frequent during the school year. The tension between Mr. and Mrs. Barton exacerbated over his lack of child support and at least once, Mr. Barton spent a week-end in jail for non-support. Sensing that Steven was holding in many angry feelings about this inter-family conflict, I asked him to draw a picture of his family, a task which he seemed to resist. When he inquired, "which family?" I repeated the instruc-



tions. He drew two figures each in a separate house, arguing on the telephone. He had covered most of the page with dark scribbles to convey much confusion, with the smaller figure uttering "but dad, I can't help it." Steven said that the houses represented his "ex-home and his real home" and added that his dad blamed him for wanting to be a part of his life. I reassured him that the problems between his parents were not his fault and that he might one day have a closer relationship with his father. For the time being, this seemed to allay some of his frustration.

With Steven's consent, we discussed these issues with his mother. I still felt that outside resources might be helpful as an adjunct to counseling. I referred Steven to Children of Divorce support group at his school and to another school program called "Everybody Counts" wherein families of children in special education visited regular classrooms to talk about unconditional acceptance of all children, despite their dissimilarities or different behaviors. When Mrs. Barton asked Steven to join her in this program, he was eager to participate. Consequently, he began to gain more respect and attention from peers at school. At T-ball games he would wave to his brother and mother and listen for Kevin to utter S-T-E-V-E-N. Kevin's teammates soon began to laugh with him.

Time passed and Steven grew much larger than his "big" brother. Steven said that he was proud that Kevin seemed to "look up" to him, and see him as the big brother in the family. One

night when Steven was watching his brother while his mother went shopping, Kevin had a major seizure. Steven raced to phone 911, and called a family friend who lived nearby. When the mother arrived home, Kevin was being loaded into the emergency squad van with Steven by his side. After that, Mrs. Barton always told him how proud she was of his bravery and his self-confidence, yet she experienced some guilt for again leaving the boys home alone, and not arranging for child care.

The divorce group and educational program on handicapped children especially seemed to help Steven's self-esteem and his role within the family. Still, there were setbacks; at age 10 he began to steal from his classmates and take off on his bicycle with his friends without telling his mother. In our joint sessions Steven said that he resented his mother's spending all her time with Kevin. Steven and his mother agreed to take responsibility for sharing feelings, negative or positive, and I helped Mrs. Barton to develop a behavioral approach to discipline.

But after Kevin turned 13, Mrs. Barton's capacity to cope with the complications of her son's Wolf-Hirschhorn Syndrome diminished. He had multiple colds, more frequent bouts of pneumonia, and cardiac episodes often involving emergency room visits at night. Mrs. Barton reduced her counseling to once a month giving Kevin's medical appointments and a lack of transportation as reasons. Still, she continued to write out her feelings in poetry which seemed to help her

cope. In one poem, she admitted to drinking as a way to survive her depression and hinted at having suicidal feelings at times.

To further complicate things, she had to have a hysterectomy at age 35, thereby relinquishing her dream of someday having another "normal" child. I called Mrs. Barton regularly, often finding it difficult to end the phone call. Sensing that she was falling short of her expectations I became more insistent about her keeping regular counseling visits. I proposed a home visit but she declined this offer. She withdrew socially and stopped taking the children to church where she had several close friends whom she had earlier described as a surrogate family. Mrs. Barton was pulling away from the support systems. One week-end, while I was out of town, Mrs. Barton made a suicide attempt by taking half a bottle of Tylenol; she called 911.

The following Monday I saw Mrs. Barton on an emergency basis and she was extremely embarrassed and disappointed with herself. I was equally disappointed, because she had gone into a shell and had allowed her problems to escalate out of control. I expressed these feelings to her. She admitted that at the time of her suicide attempt she had not thought of what might happen to her children, causing her again to evaluate her parenting role as "a zero." I felt she desperately needed to structure some individual time for herself and she agreed. She began to take private guitar lessons after I arranged for subsidized respite care two evenings per week.

Mrs. Barton learned quickly and began to set some of her poems to music. After a few months she and her friend Sheila presented a Christmas concert for the children in our convalescent hospital and constructed hand-made instruments for everyone. I was proud to cheer her on and the children loved the special attention. Meanwhile, in play therapy Steven became quieter and showed little interest in puppets or other play materials. I sensed that Steven needed to spend more time in recreation away from home and needed a regular adult male role model. I suggested a Big Brother though the waiting list was unending; but, Mrs. Barton persisted and eventually obtained a Big Brother by having Steven go on a "Thursday's Child" television program. Steven spoke excitedly about his Big Brother and was proud when the local paper featured an article about them and a karate class they were taking together.

When Steven was eleven and Kevin was fourteen there were other major hurdles to face. The Bartons had been attending the same church for several years, and Mrs. Barton was grateful for her church "family" whom she saw as a godsend. The year Kevin had walked, the church congregation arranged a special processional recognizing him as the "first" child with disabilities to be part of their congregation. The church had extended other favors to the Bartons, such as lending them money, providing transportation, and putting a down payment on their car. As a way to give something back, Mrs. Barton typed the church newsletter and

helped with other volunteer activities. On Sundays when Steven went to church for preparation for confirmation, Kevin tried to follow him. Mrs. Barton did not think about it any further until Steven had taken his first communion. Kevin had continued to go up to the altar with the little children for the traditional Sunday Blessing. Steven asked her one Sunday why Kevin could not be a "full member of the church, like me?" Almost instantly she agreed, "why can't he?"

This was a difficult challenge, more so than previous advocacy efforts. There were many meetings with members of the congregation who expressed feelings of betrayal, and annoyance at the ingratitude of the Bartons. Some church council members reminded the family that the church had always been there for the them, even when they were alone and when the public assistance cupboards had run bare at the end of the month. Even the pastor whom Mrs. Barton had considered a close friend, spiritual guide, and mentor moved toward the opposite end of the theological discussion of whether Kevin could possibly "understand" the meaning of full communion with the church.

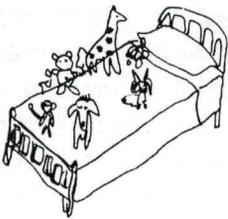
Mrs. Barton came to counseling regularly and seemed to need reassurance that she was doing the right thing. I supported her advocacy and did not see what intelligence had to do with one's right to worship. As we explored the issue, Mrs. Barton said that, first and foremost, if she and her children could not be treated as a normal family at church, then what could they expect within

society at large? Visits to the local bishop's office and regional church council meetings consumed much of Mrs. Barton's time. Steven often insisted on waiting outside the conference room at the church. In the joint meetings we discussed the contentment which Kevin's "full" church membership might afford the family and him. As usual, the mother and I explained these actions to Kevin, despite our inability to know his level of comprehension because of his profound mental retardation. Then one day Mrs. Barton and Kevin arrived at counseling with big smiles on their faces. They had won their petition for Kevin to be confirmed. The family could now worship in full communion with the church and each other.

But almost in the midst of this victory, a darker shadow emerged. One morning Mrs. Barton appeared at my office door in tears, with Kevin's hand in hers. They had just returned from the cardiology department and the doctor had announced what she had known might one day be unavoidable. Kevin had to have open heart surgery, which carried less than a 50-50 chance for survival. We talked about available options and she decided that Kevin must be given this chance. As was customary in our sessions, she knelt down to where she could be at eye level with Kevin and get his attention. As she explained her desire for him to have the heart operation, Kevin repeated the words "yeah," and "o.k." several times; at some level, he seemed to comprehend the gravity of the moment and the seriousness in his mother's voice.

We both told him that the surgery might help him to feel better and have a longer lifespan.

The Cardiology department informed Mrs. Barton about "Make A Wish" which grants "last" wishes to children with terminal and life-threatening medical conditions. With the surgery two weeks away, Mrs. Barton arranged for Kevin's "wishes" to be granted. He loved music, especially country music; needed a new bed, and cherished his stuffed animals, many of which were now frayed and coming apart. Steven took a real interest in the plans to surprise his brother with "wishes" and I sensed that the planning and anticipation took their minds off the surgery. Within a few days, "Make A Wish" gave Kevin a new stereo system, stacks of tapes and records, and a new bed covered with stuffed animals of all sizes, including a giraffe.



When I made a home visit the day before Kevin's surgery, the house was buzzing with laughter. Mrs. Barton's friend, and Steven were dancing with his brother to a Dolly Parton song. They were intoxicated with the moment. I noticed that Kevin would go into his room and take a new stuffed toy from the bed and bring it back into the family room. Mrs. Barton stepped into the kitchen and began to cry, not wanting the children or Sheila to

hear. I followed her and we talked about all that Kevin had been through. She even managed a smile when I mentioned his self-proclaimed motto, "I'll be right back." She questioned whether she was making the right decision. I assured her that I would be with her before Kevin's surgery the next day and that we would again discuss with the surgeon the risks and benefits involved.

On Friday morning in the surgical waiting room Mrs. Barton was surrounded by her pastor, Sheila, neighbors, members of the congregation and the hospital chaplain. We sat and talked and the surgeon briefly discussed last minute questions and reviewed the procedure. Later, Mrs. Barton said that she had not wanted Steven to miss school that day, although he had begged to come to the hospital. She thought his being there would be more stressful for him, but allowed him to spend the evening before at Kevin's bedside.

A nurse and an orderly wheeled Kevin toward the main surgical corridor. Mrs. Barton and I walked over and she took his hand. To my amazement, Kevin was clutching the stuffed giraffe tightly in his other hand. Mrs. Barton looked at me and said, "I know, isn't that something, it's from "Make A Wish." Of all the toys on his bed he had picked the giraffe. At that moment, we felt the bond of hope that had begun with his brother Steven's earlier crayon drawing of the giraffe.

Several weeks later, I looked down the hallway to see Mrs. Barton, Steven, and Kevin heading for the Social Work Department. Kevin was still clutch-

ing his stuffed giraffe and his brother was playfully teasing him. Kevin had proven his resilience and defied the odds once again.

ENDINGS

Within a year of Kevin's surgery I left the agency to take a faculty position across the state. As I look back on my work with this family over 9 years, I realize that Mrs. Barton experienced much difficulty in accepting her right to be happy and to lead a full life. This was not surprising considering the number of times she was abandoned or abused, by men in particular. In high school, after saving money for months from baby-sitting to buy a beautiful prom dress, her father sexually abused her on the way to the dance. When she "finally" was able to have a "normal" son, three years after giving birth to Kevin, her husband informed her, even before she left the hospital, that he was having an affair. And, on the eve of her Hawaiian vacation, she had been jilted by her boyfriend. I feel successful in having brought her to an awareness in counseling that she had to sometimes put herself first in order to become the best possible parent for her two sons. Through the referrals to the children's divorce group, the parents' sharing program, respite care, and Big Brothers, I helped the family to live a more balanced life, despite Kevin's excessive care needs.

As I reflect on the strategies and techniques used to assist Mrs. Barton and her sons, I realize that my approach was to help the mother take responsibility for major decisions that would affect

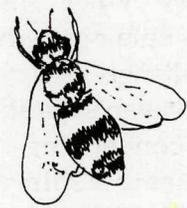
the family. This method seemed conducive to helping her cope with internal struggles and assisted her to engage multiple community resources, which her son would require throughout his life. At first, she blamed herself for her turbulent childhood and failed marriage which in turn led her to lack confidence in trusting men or developing intimate friendships. She often believed that others would judge her immediately as a "welfare mother" or single parent.

As a result of my encouragement to join parent forums and support groups on coping with children with multiple disabilities, Mrs. Barton learned that sharing and discussing mutual concerns with other parents could be a great source of strength. She often reflected on small comments and words of inspiration from other parents despite the fact that their children's disabling conditions were very different from Kevin's Wolf-Hirschhorn Syndrome. And, through discussions with other parents, she learned of national parent coalitions and advocacy efforts and became interested in contacting other parents of children with Wolf-Hirschhorn Syndrome. By advertising in a parents' magazine, she located several parents of such children with whom she could respond by writing and occasionally telephoning. Since all these families had younger children, she prided herself in being the "expert" who could inform them of her own parenting challenges and ethical dilemmas regarding life-threatening decisions, school programming, and attempts at mainstreaming.

REFLECTION

As a counselor, I at first used a client-centered approach with Mrs. Barton but this proved to be ineffective as she tended to become increasingly disenchanted as she discussed problems, such as her fights with her ex-husband, feelings of guilt about wanting a "life of her own," and her struggles to be an adequate parent. I remember sharing these early frustrations with a colleague in a team conference and he said that Mrs. Barton might have saved herself and Steven from a life of tragedy if she had just placed Kevin in an institution. But I did not give up. In counseling, the mother failed to gain much insight from lengthy discussions which I felt were beginning to foster dependency and manipulation of the therapeutic process. For instance, at times I had difficulty introducing new ideas or even making suggestions. There were times when I doubted that my intervention was having any effect on this family. When we began to focus on Mrs. Barton's and the boys' successes and strengths each week, it became much easier for the family to address present and future challenges and also take more responsibility for their decisions and actions.

As Steven moved into the middle childhood years, he gained a better understanding of the importance of owning his feelings and behaviors as opposed to hiding or denying them. These realizations enhanced family communication and trust between Steven and his mother. A



reality therapy approach amplified the mother's ability to view herself in a more multi-dimensional sense as a whole person. As described earlier in this narrative, she began to enjoy writing out her feelings, often in poetic or musical lyrics, which in turn inspired her to take guitar lessons. She copyrighted several of her country songs and at the encouragement of her guitar teacher sent a few songs to Nashville to be considered for the music industry. Slowly she was able to discover and celebrate her personal talents and thus move beyond seeing herself as "just a parent."

From writing this narrative, I realize now that I sometimes used my work with the Bartons as a frame of reference for counseling other families of children with disabilities. I know that I sometimes consciously and perhaps unconsciously had the Bartons in mind when I encouraged other parents to celebrate even the small successes and gains in their children's development and to always think of expecting more. I even quoted to a struggling mother what Mrs. Barton once said, "A bumblebee would never fly if someone told it that in reality it wasn't supposed to be able to do so." And I am also very much aware that my work with this family helped me to cope with problems in my own life and practice as a social worker

and teacher. When I face a rule that seems unfair or perhaps warrants a challenge, I am more likely to model Steven's question to his mother concerning Kevin's church membership and say, "Why not"? And every time I see a stuffed giraffe in a toy store window I smile and think of the fortitude of a parent and the inspiration of a little brother whose hopes and love helped to raise his big brother aloft to face incredible challenges.

CODA

I occasionally hear from Mrs. Barton via a call or letter. Steven decided to live with his father out-of-state for awhile, but this arrangement failed and he soon moved back home with his mother and Kevin. He and Kevin are said to be as close as they ever were. Steven works as a lifeguard at the YMCA and helps to look after his "big" brother while his mother works out. Meanwhile, Mrs. Barton continues to be a strong advocate for herself and her children. She attends the local community college where she is completing a degree in travel and tourism. In 1991, the Bartons attended the first annual conference for children with Wolf-Hirschhorn Syndrome and their families, called "Dancing with Wolves" in Des Moines, Iowa. At the conference, the family learned that Kevin is perhaps the oldest child still living with Wolf-Hirschhorn Syndrome. Steven now loves to quote this statistic to his friends.

In addition, the mother has taken a leadership role in expanding local parent groups and

has managed to lease a three bedroom house for her family through a special entitlement program available to parents who are willing to provide ongoing in-home care for their disabled child. She states that in "in his own way" Kevin has been an inspiration for both Steven and her; through his perseverance and will-power, he has motivated them to be more tenacious and goal-oriented themselves. She says when she observes Kevin's great struggles to accomplish even the smallest of tasks, her challenges by comparison seem minor.

Mrs. Barton stated with confidence that she has never regretted her decision not to place Kevin in an institution. Kevin now functions developmentally at around 15 months and attends a multi-handicapped class at the local high school. In one breath, Mrs. Barton talks about Steven's successes with the drama club and school paper, and just as quickly beams over Kevin's ability to wipe off tables in the school cafeteria and repeat several new greetings. And, she really looks forward to next Spring when both Steven and Kevin will graduate from the same school-together. Kevin continues to ride high on the back of his giraffe, with his "little" brother Steven sitting right behind him. □

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