

CHAPTER 17 A Pier Full of Empty Wheelchairs

“It is in games that many men discover their paradise.”

~Robert Lynd

Recreational opportunities for children with disabilities are few and far between. For those children who also suffer the added disability of poverty, the opportunity to experience the sheer joy of participating in any sport is less than non-existent. Participation in sports, for them, exists only in their imaginations.

Children who have disabilities can be so far removed from the recreation, sport, and social activities that are routinely offered to able-bodied children that they retreat to their homes, with little hope of any meaningful participation. The closest most children with a disability come to sports is watching their able-bodied siblings from the sidelines.

Slowly and painfully, the seemingly endless activities that many able-bodied children take for granted become daily reminders of an improbable dream for a child with a disability.

Tom Richey was the Sports Director of the Rehabilitation Institute of Chicago. Since 1982, RIC Sports, through its Virginia Wadsworth Wirtz Sports Program, has been offering adults with disabilities, opportunities to participate in a wide variety of sporting and recreational activities, ranging from golf, softball and tennis to wheelchair basketball and Quad Rugby.

Until the year 2000, RIC Sports programs were limited to adults. When I called Tom Richey early that year to inquire about the possibility of expanding RIC's programming to include children with disabilities, he was amazed. Tom said, “We just scheduled a meeting to figure out a way to do just that! Would you like to come to our meeting next Wednesday?”

I certainly made time for that meeting. As is often the case when good intentions are put forth, good people show up to help make them happen. Tom Richey is one of those good people, and Tom and Dreams for Kids were a match made in paradise.

After a series of meetings, we wasted no time in initiating the RIC Dreams for Kids' Summer Camp. In the summer of 2000, during our first year with RIC, we offered ten children with various forms of disabilities, the opportunity to play the sports of their dreams every Saturday. We called the pilot program, ‘Super Summer Saturday Sports.’ The next year, we dropped Saturday from the name as we added two additional days each week to the program. By the third year, in 2003, the demand for the program was overwhelming and the effect was everlasting.

Our sports program for children with disabilities is now a full summer camp with special activity days and additional trips offered throughout the school year. Not content with offering just the standard fare to children who had been denied access for a lifetime, we offered, in addition to gymnastics, baseball, softball, tennis, basketball and golf, activities as diverse as rock climbing, kayaking, martial arts, yoga, horseback riding, water skiing and sailing. Just to make sure that the kids had enough to talk about in school until they got back to camp the next summer, there were trips to the zoo and to water parks.

Each year we expanded our program to accommodate a growing waiting list of eager children anxious to find out if it was really possible to realize a dream they had believed to be impossible.

In late 2006, the profound impact that the sports program was having on the children and their families increased our vision, and we began to see the necessity to reach out to as many children as possible. With great excitement and anticipation, we hired Tom Richey as our organization's Executive Director and developed plans to increase our programming opportunities within our area, across the United States, and into places in the world where children with disabilities are virtually hidden from society.

With the beginning of the eighth year of our program, we are convinced of the importance of this effort, and that the sheer joy of being able to come from the sidelines of life and play sports literally changes lives.

Changing Lives... One Kid at a Time...

*"Unless someone like you cares a whole, awful lot; things
aren't going to get better, they're NOT!"*

~ Dr. Seuss, *The Lorax*

Changing Lives...One Kid at a Time...is the "tag line" of Dreams for Kids. Yet being described as something that is tagged on, hardly does it justice. The lives that have been changed in the work we are fortunate to do are not just limited to the kids who participate in our programs. Parents, brothers, sisters and entire families have been affected in ways that give such enormous hope.

Volunteers have rediscovered the joys of childhood and the immeasurable value of giving that has carried over into their own lives and their families.

Sports can be viewed as a day's activity and as an opportunity for recreation. However, those who are denied participation in sports realize from afar the greater value in playing the games. There are friends to meet, places to go, and competition to expand one's confidence. Above all else, there is the essential feeling of belonging. For a child to be part of something that, previously they could only witness on television or from the sidelines, liberates them in a way that carries over into the rest of their lives.

Living with a disability can too often be thought of as living with a limitation. When children who are disabled are denied opportunities that are readily available to able-bodied children, this assumption can be reinforced. Once those obstacles are removed, the word limitation is to never return. The positive effect carries over to school and to their social lives. Roles are reversed in families that longed for that reversal and lives are never the same.

Sean is a young boy who has cerebral palsy. Sean's older, able-bodied brother is a high school soccer star. For his entire life Sean has cheered his brother from the sidelines. There has never been a fan more enthusiastic or more loyal than Sean. Sitting next to his parents, Sean's cheers can be heard across the field, and probably down the block, every time his brother comes near the ball.

The introduction of Power Soccer became an open invitation for Sean to come from the sidelines of life, and for his parents to do what they always dreamed of doing. It was also an opportunity for Sean's brother to cheer for his hero.

In the winter of 2006, on a Wednesday night, in a Chicago indoor gymnasium, young Sean was motoring his chair toward the ball with a smile from ear to ear. From the first row, cheering on their feet and from the bottom of their hearts, were the proudest parents and brother you could ever imagine watching a soccer game.

When we asked Sean if he was having fun, he didn't have to smile, because that grin had never left his face from the moment he rolled onto the court. Sean just looked straight up and said, "*Ohhh, my mom is going to be sooo proud of me!!*"

Fifteen Feet of Joy

"Yes you can....but you ain't alone. I'm right here with ya. I've been here all along. Now play the game... your game. The one that only you was meant to play... The one that was given to you when you come into this world... You ready? Strike that ball Junuh....don't hold nothin' back. Give it everything...Now's the time. Let yourself remember... Remember YOUR swing."

~The Legend of Bagger Vance

I love reading the Dreams for Kids' schedule of sports for the summer. There is not a kid alive that would not be envious of the wide range of fun and challenging sports that fill the schedule. It is ever so sweet that the kids who are participating in our program are experiencing the very idea of sports for the first time. Now they can go back to school and be the envy of everyone. They can go from being the one left out, to hearing the words, "You are so lucky!"

One such sport is golf. At some point, most able-bodied kids have the opportunity to try their hand at this game, but for those with disabilities, there is not much of a chance to tee it up. We offer golf instruction from volunteers, such as Patrick Byrne, who lost his leg as an adult and has dedicated his life to inspiring others with disabilities. Patrick could not drive a golf ball more than 40 yards after his injury. With an athlete's heart and dedication, he now reaches over 250 yards from the tee, while balancing on one leg! He even won the longest drive contest at our organizations annual golf outing.

However, the highlight for any golfer is not the driving range but rather, getting out on the actual golf course.

For it to be any golf course would be fine indeed for these kids, but if it is worth doing, it is worth overdoing. After all this *is* a dream summer. So our day on the links is at the private Merit Golf Club in Libertyville, Illinois, home to prestigious members, including a couple of guys named Tiger Woods and Michael Jordan.

The day begins like it does for any other golfer on the course—at the practice range, with a bucket of balls. However, the members and guests of the John Dolan Golf Challenge that share the range with us that day do not have it so lucky. We bring a PGA Pro or two for some last minute instructions.

After practice, it's time for a picnic lunch under the willow trees and then it's off to play the game. Our kids now have the opportunity to not just play on a golf course, but to play on the same course as Tiger Woods. I will never forget one year when Jonathan,

who uses a walker that was his grandmother's, and is about chin high, was pacing anxiously all through lunch, constantly asking, "Where's Tiger? Where's Tiger?"

It was time to line up on the first tee and in convenient sixteensomes; we were ready to play the course. One by one, each kid took his best swing on that tee, on the first hole of the Merit Golf Club. Many of the kids were in wheelchairs, some with braces, walkers or crutches, some missing an arm or a leg, or some had other visible disabilities. However, for that moment, every single one was a golfer.

I watched until the last golfer took his swing and then looked out across the fairway. There was not a single golf ball that landed more than fifteen feet from the tee. I will always remember looking next to the group of kids scrambling to their balls to set up their next shot. In a precious moment in time, it was as if all of their hardware had just disappeared. They were just like any other kid, filled with one unmistakable emotion—pure joy.

I have reflected on that scene often. When I do, I try to remember that no matter where I am, whether at work, at home, or playing a sport, when I take my very best shot—and it only goes fifteen feet—I look up and smile, joyful for simply having the opportunity.

After a round of golf, it is time for the ceremony on the 19th Hole. Each golfer receives a Champion's Cup. There is a picture of Jonathan from our website, which sits on my desk at home. He is holding his Cup high above his head, with a look of pride that could match anyone who has ever worn the Green Jacket at the Masters.

As we were leaving for the day, Jonathan, holding his Cup under his arm while managing his oversized walker, stopped and put his head way back so he could see me from under the brim of his golf cap. With all seriousness, he said, "If you see Tiger—tell him I can golf!"

A Lake Touched by God

*"When we try to pick out anything by itself, we find it
hitched to everything else in the Universe."*

~ John Muir

The broad spectrum of sports our organization made available to children with disabilities continued to expand in our program, and with its expansion came memories to last a lifetime, coupled with enough dreams to fill the future for a summer full of elated kids—and their parents.

One of the featured days of our summer long camp is a water sports event held at Twin Lakes, Wisconsin. There is no finer example of a day that can transport one from the feeling of being left out, to being on top of the world.

There is a certain beauty to being on the water; or sitting on the shore or pier, just gazing at the waves of water. There is a beautiful mixture of action and serenity, as boats and watercraft intermittently speed past, only to leave the water calm once again, as the sun shines across the horizon, making it appear to stretch on forever.

There is also great hope in just being near the water. It has been said that water is where it all began and where we shall return. The vast waters are also home to the dolphins. On this one day, in rural Wisconsin, the water is a place where dreams live.

We arrive with the rising of the sun, with a band of excited volunteers, and after a group breakfast, we head to the pier to set up for the day. There is a canopy for us to set up over the length of the pier, water craft to line up, and two power ski boats to gas up and to get ready to launch. On the beach, lines of kayaks and floatable chairs wait in the sand at water's edge. The sound system needs fine-tuning and there are banners to be hung and flags to be raised. There is a half drum to fill for the barbecue lunch. Finally, after the life jackets and vests are hauled out, it is time to fill the parking lot with adaptive bikes and to mark off the obstacle course.

This is no ordinary day at the beach.

As we set the stage for this little corner of paradise and look out over the adaptive equipment, which now stretches from the parking lots to the beaches, and covers the pier and fills the water, we think of the nearly one hundred kids, with various disabilities, who are now at home, miles away. Soon they will be boarding a bus toward a day that has existed only in their imaginations.

Envision the uncommon scene of busload after busload of “disabled” children arriving at the beach. Now imagine a stream of those kids arriving there for the first time ever, flowing from the parking lot, eyes wide, smiles even wider, heading to the water, some with crutches, some on walkers, others in wheelchairs, some in braces and still others being carried by their parents or friends. There may be a better way to start a day, but I have a hard time thinking of what that would be.

Once the day officially begins, surrounded by serious organization, training and watchful supervision, it is a complete free for all—just what any kid would order.

On the beach and on the pier, the initial unbounded enthusiasm gives way to what is often seen when any kid experiences the unknown for the first time. “There is no way I am going on that!” “That” is this: water craft rides, kayaking, riding a bicycle for the first time, floating in the water in a beach chair, or the highlight, being pulled behind a boat around the lake on water skis, at faster than bargained for speeds. One by one, each kid gathers the courage to try “that” and eventually all of “that,” and cannot be pulled away.

After a traditional barbecue lunch, there is time to sit around and listen to the excited chatter of a happy bunch of kids. The second half of the day is more and more of the same. The grand finale is a water show presented by the famous Aquanut Water Show Team.

Of the many activities our organization has made possible, one that is particularly special is the magic of water skiing, now available for those with even the most severe disabilities. As we purchased pieces of equipment, one by one, the most prized piece is a simple, yet powerful piece of adaptive equipment; the outrigger ski and companion chair, one of several pieces of adaptive equipment contributed to the program by the engineering students of Northwestern University.

This adaptive equipment allows a child to be strapped into a chair, which is attached to two extra skis, one on each side of a single ski in the middle. The equipment is pulled by a special ski rope attached to the ski boat. Trained interns ride in watercraft alongside, as the boat speeds along the perimeter of the lake. We pull out the full guard of at least eight interns, riding two to a watercraft, when our resident quad, J.J. O'Connor, takes to the water, and of course, elects to drop the outriggers. This makes for some interesting moments, but the sight of J.J. sailing past the pier on his first fly by, arm raised, is one to truly treasure.

As kids witness others with disabilities take on such challenges, each become inspired to do more, and the result instills them with a confidence that carries over, not just for a day, but for the rest of their lives.

During one of our ski events, as I was walking to the parking lot, I saw an older man slowly walking with his hands in his pockets, appearing to be lost in thought. I waved as I approached him and he said hello. When I introduced myself, he said he was Chris's father, one of the kids in our camp. Chris is sixteen-years-old and was born with a severe neurological disorder, which has confined him to a wheelchair since birth.

Chris's father told me that he was on the way to call his wife and was trying to collect his thoughts. "This entire day has just been so overwhelming to me," he said. "My wife and I never imagined that our boy could play a sport, even though that is what he has always wanted to do. Now he has played all kinds of sports, all summer long, and today he is actually going to water ski." His voice broke as he struggled to control his emotions, "All of you must have been touched by God to have given my son so much happiness."

Later that same day, I sat down on the pier to collect my own thoughts, as another young man, Marcus, was being returned to his wheelchair after his third water skiing trip around the lake. With a towel on his shoulders and water dripping down his face, he looked out over the lake. The sun was beginning its descent, casting a glow on the water. Marcus quietly said, "This is really something." I replied that water skiing is really a great time. He looked at me in disbelief. "Water skiing? Man, I have never even seen a lake. I have never been on a pier. I didn't think that I would ever be on a boat. For kids like me, this is just unbelievable."

I could not resist asking him if this was a dream come true. I got what I deserved for fishing for the easy one—a dose of reality. "Dream? I would never have dared dream about something like this."

Another Day in Paradise

"Forget yourself for others, and others will never forget you."

~ Author unknown

Over the past seven years, I have witnessed the sports program grow in ways which none of us could have ever imagined. It is not just in the increased number of children who now participate in the program that gives us such great hope. It is in the growth of the kids who have participated. It is also in the profound changes that have occurred in those who have reached out to these children. Every single year, the effect of the program continues to change my own life. One by one, I have witnessed the simple act of reaching out having a life changing effect on those who show up to volunteer for the first time.

Just a few months ago, at the beginning of our water sports day on the lake, I was telling a first-time volunteer about Chris and about meeting his father. I had not seen Chris for some time nor had I seen his father since that day. We were walking up the hill in Twin Lakes, toward the parking lot, and I suddenly stopped. I was standing at the exact same place where I had said hello to Chris's father years before. The emotion that came

from that realization literally stopped me in my tracks. What was to happen next would remind me that there are greater forces at work in our lives, and it is in these moments that we realize that we are never alone.

As we stood on the place of that special meeting with Chris's dad, I had to take a moment to attempt to control my own emotions. As I looked up and toward the parking lot, I saw that the busses had arrived and the children were beginning to line up. I looked at our volunteer and looked back at the kids without being able to say a word. The first boy in line was Chris.

We walked up to meet the kids and when I said hello to Chris, he was attempting to say something to me. Chris's condition makes it very difficult for him to speak. I leaned in very close, and he said in a whisper, "I remember you."

One Special Day

"There are no great things, only small things with great love. Happy are those."

~Mother Teresa

Throughout the day, our newest volunteer was quiet, yet very engaged with the activities. At noon I asked her if she would like to go with me to take Chris on a Jet Ski ride. The kids were just finishing lunch and as we walked under the big oak tree to see them, Chris knocked over his plate. His aunt laughed and said, "When he sees you he jumps with excitement." We did not have to ask Chris twice whether he wanted to go on that Jet Ski ride. Chris absolutely loves the water and especially loves Jet Skis.

For someone with Chris's physical limitations, it is important to ride three to a Jet Ski so that he can be secure in the middle. The first order from Chris was to "go fast." Of course that directive was followed without any hesitation, and we soon received our first warning of the day for speeding away from the pier.

Continuing to follow our orders to go fast, we pretty much made a nuisance of ourselves to every water skier or boat that was unlucky enough to be in our path. Then, in a moment I will always treasure, Chris tapped my shoulder several times and as I leaned back to see what he wanted to say, he rested his head on my shoulder and very quietly said, "Let's just go slow."

Time stood still as the three of us silently drifted along the calm lake on that beautiful day. It is a moment that I wish could have lasted forever. I realize now, that moment will be forever.

At the end of another special day, we all said our good-byes and it was then that I recalled the words told to me by an old friend, "For those who love, there are no goodbyes, for we are forever connected in our hearts."

A few days after the event, I received a letter from the volunteer who rode with Chris:

Than you so much for including me in the Dreams for Kids' family. It was such an exhilarating day for me. You have given kids with disabilities the opportunity to be "kids" and enjoy something as simple as going for a boat ride, or a Jet Ski ride, or even, God forbid an actual chance at skiing.

These kids have a whole day when they can toss aside their ACL's and crutches and wheelchairs and just be a kid. A day when these kids are surrounded by other kids, just like them. For once, they are the "in" crowd, the majority. They are respected, honored and cherished for all of their Abilities. We, in fact, are forced to step out of our world and up into theirs. It's an enlightening and rewarding experience that's very hard to capture in mere words.

As a parent of a special needs child, I can tell you how unique your organization is and how honored I am to have been a part of one special day.

*Thank you
Shawna Egan*

Sailing Away from the Chair

"How wonderful that no one need wait a single moment to improve the world."

~Anne Frank

As the summer winds begin to fade and the air turns brisk at night, there is more than just fall in the air—school is right around the corner. There is no better time than this to take a sail, way out on the expansive waters of Lake Michigan, along the fabulous Chicago Skyline.

Our annual day of sailing begins at Burnham Harbor, graciously sponsored by Judd Goldman Adaptive Sailing. Surrounded by the largest of luxury boats and yachts, the kids throw a line in the water and try to catch that elusive fish. We are not counting on the catch to be our lunch, so a barbecue at water's edge is the order of the day.

Near the end of lunch, the kids suddenly become quiet and still as the adaptive sailboats, six in all, approach the pier.

The sailboats are large, but the type that allows you to touch the water if you lean over the side, an experience some of the kids will have that day. Each boat is also equipped with special chairs to strap in kids who do not have the ability to hold themselves upright.

This particular day was an especially beautiful one, with a slight breeze on calm waters, and with the sun periodically breaking through passing white clouds. As we loaded up the kids onto each of the sailboats, I got into the last boat and remember thinking how perfect the sky and landscape appeared.

As the parade of boats left the harbor, I could not help but smile at the sight. Six boats full of the most excited and happy kids you will ever find, sailing toward the free and open waters of Lake Michigan.

As the large boats from the harbor passed alongside of us, their captains waved, smiled, and said "Hi."

As the winds caught our sails, the kids cheered. As we sailed away, the sun broke through the clouds and was shining brilliantly. I turned back, and will always feel blessed that I did, for there was the most beautiful and breathtaking sight...*a pier full of empty wheelchairs.*

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